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PRINCIPLE INVESTIGATOR: Suzanne M. Miller, Ph.D.

CONTRACTING ORGANIZATION: Fox Chase Cancer Center
Philadelphia, PA 19111

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14. ABSTRACT

Approximately 20-30% of women develop lymphedema (LE) following breast cancer treatment. Effective symptom management requires that women recognize early signs of lymphedema, and maintain precautionary practices over time. Data indicates that knowledge and use of symptom minimization precautions are poor. Little is known about how breast cancer survivors perceive their *LE* risk, and the cognitive-affective factors that promote the uptake and adherence to *LE* symptom minimization precautions. Guided by the Cognitive-Social Health Information Processing (C-SHIP) model, we are conducting a longitudinal study, to assess barriers and facilitators associated with knowledge and adherence to *LE* symptom-minimization practices among breast cancer survivors. We are exploring the mediating role of cognitive-affective variables, and the moderating role of attentional style, on knowledge, uptake and adherence. Our preliminary analysis shows a correlation between high monitoring and more knowledge of lymphedema risks compared to low-monitoring styles. We are surveying levels of knowledge, and practice of symptom minimization precautions at baseline, 6-, and 12-month follow-up. Although many women are aware of LE minimization practices, data suggest that they are not incorporating the recommendations into their daily lives. Further, psychosocial factors play a role in the uptake of LE symptom-minimization practices, and sustained adherence over time.

15. SUBJECT TERMS

Breast cancer survivorship, Lymphedema, Prevention, Psychosocial Factors

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Table of Contents

INTRODUCTION

Improvements in breast cancer treatments have greatly reduced mortality rates (Petrek 2000; Passik 1998; Erickson, 2001; Tasmuth 1996). The number of breast cancer survivors continues to increase due to improved methods of detection and treatment. Consequently, more women are dealing with the impact of lymphedema on their everyday lives and well-being (Armer, J.M. et al., 2005; Jeffs, 2005). Thus, it has been recognized that greater attention needs to be given to survivorship issues, such as the management of post-treatment side effects such as lymphedema (LE), that compromise physical and psychological functioning and quality of life (Passik & McDonald 1998; Erickson, Pearson, et al., 2001; Brenes, Mihalko, et al., 2001). Yet, little is currently known about women's knowledge and practice of precautionary behaviors to prevent or lessen the impact of this condition (Coward, 1999; Clark, Wasilewska, et al., 1997). Guided by the Cognitive-Social Health Information Processing (C-SHIP) model (Miller, Shoda, et al., 1996; Miller & Rodoletz, 1996; Miller & Diefenbach, 1998), the overarching objective of the present study is to explore the cognitive–affective factors associated with knowledge about LE symptom-minimization practices, their initiation, and the sustained maintenance of these practices among breast cancer survivors currently unaffected by LE.

The specific aims of this project are as follows:

Aim 1: To delineate the underlying cognitive-affective mediating mechanisms (i.e., women's self-construals, expectancies, values and goals, affects, and self-regulatory strategies) that facilitates or undermine the uptake of LE symptom-minimization practices, and their sustained adherence over time. These cognitive-affective patterns will be assessed and related to levels of knowledge and the practice of symptom minimization precautions, at three points in time: baseline (within 6 weeks post-surgery), and again at 6- and 12-month follow-up post-baseline. It is hypothesized that greater LE-knowledge, greater intent to establish practices and/or adhere to existing practices, as well as greater uptake of recommendations and sustained adherence will be associated with heightened risk perceptions; greater self-efficacy, greater perceived benefits of, and fewer barriers to, enacting symptom minimization practices; lower LE-related distress; and greater ability to perform self-regulatory strategies.

Aim 2: To assess the moderating role of stable differences in the individual's cognitive-emotional profile or "psychological signature" on the uptake and adherence of LE symptom minimization practices and personalized cancer threats and challenges, over time (Miller, 1995). Specifically, it is predicted that high monitors (who attend to, focus on, and personalize cancer threats) will show greater knowledge, uptake, and adherence than low monitors (who distract from and downplay the significance of cancer threats and challenges).

To accomplish these objectives, we are conducting a longitudinal study of LE symptom-free women who are in remission following sentinel or axillary node surgery for Stages I-IIIa, primary breast cancer ($\underline{N}$ = 178). From two recruitment sites, the Breast

Evaluation Clinic at Fox Chase Cancer Center and Virtua Memorial Hospital, a nurse educator and a primary site coordinator, Dr. Eric Miller, respectively, make potential participants aware of the study through the provision of a leaflet describing involvement in the study upon registration for their clinic appointment. A member of the FCCC research team reviews FCCC's electronic medical records, the Soarian Clinical Access Database to identify clinic patients and to determine patient eligibility (i.e., diagnosis, surgery status). The research staff then contacts eligible patients by telephone to describe the study, solicit participation, and obtain verbal consent for participation. Eligible, consenting participants then complete psychosocial measures and a written informed consent at their next post-surgery follow-up appointment, usually within two weeks of initial contact and consent. Upon completion of the baseline questionnaire, each participant is given a copy of the American Cancer Society Lymphedema booklet containing hand and arm care following surgery or radiation therapy for breast cancer and the recommended precautionary actions that they can follow will be briefly summarized verbally. Relevant psychosocial and behavioral variables are reassessed by telephone at each of the follow-ups, 6- and 12-months post-baseline. Participants who experience a breast cancer recurrence are excluded from follow-up and will be replaced in the study design.

BODY

During year 1, the plan was to initiate Tasks 1 and 2 and complete Task 1, as outlined in our approved Statement of Work.

The specific aims of Task 1 were:

a. Modify provisional measures according to Institutional Review Board (Months 1-2)
b. Establish Recruitment Procedures/ Train Staff (Months 1-2)

Task 1 was accomplished according to schedule.

The aims of Task 2, are:

a. Recruit Participants, Conduct Longitudinal Study (Months 2-60)
b. Establish Database and Enter Data (Months 2-60)

Recruitment has been slower than expected primarily because of temporary staffing shortages which have been resolved. New staff have now been hired and trained in recruitment and study procedures. On August 15, 2006, Fox Chase Cancer Center (FCCC) sent a formal request to further extend the period for additional 12-months for no additional funding support in order to fully complete Task 2 and Task 3. This extension would allow the continuation of recruitment in order to reach the original recruitment targeted sample numbers (N = 178), and to complete data analysis and publications reporting upon the work. Further, two amendments to the protocol were made over the past year.

1) In March, 2006, the annual IRB approval was provided for the new HIPAA form for an updated version of the form that is standard to the Population Science Department at FCCC.
2) In April 2006, a modified medical care language in the consent form was approved.

The aims of Task 3, initiated in year 1 and continued in year 5 are:

a. Analyze Preliminary Data (baseline to 6-month and 12-month follow-ups) (Months 4-60)

b. Annual Reports Prepared (Months 4-60)

To date, preliminary baseline data have been entered and descriptive statistics have been performed. Since August 15, 2003 a total of 1417 patients have visited the Breast Evaluation Clinic at FCCC. Since August 2003, 325 of the 1417 clinic patients (23%) have been identified as eligible for the study (i.e., early stage at diagnosis, LE symptom free, receiving treatment at FCCC). To date, of the 325 eligible women, our research team has successfully contacted 183 (56%) by using a maximum of 20 attempts to contact women by telephone. Of the women contacted, 158 (86%) provided verbal consent to participate. Ninety-nine of the women contacted (54%) declined participation with 85 women stating that they were "not interested" with no additional explanation provided and 14 women cited non-study specific related factors (i.e., language/communication barriers, already participating in another research study, lack of transportation) as reasons for non-participation. To date, 85 of the 158 consenting eligible participants have completed baseline data. Thirty-two originally consenting eligible participants have attrited from the study (18 participants through passive attrition [i.e., not showing up; not returning telephone calls], 14 participants through active attrition [i.e., changing their minds about participation.]). Collection of six-month follow-up questionnaires began in August 2003 and 62 questionnaires have been completed. To date, six women will soon be due for their 6-month follow-ups. Twelve participants failed to complete their 6-month follow-up in the allotted time. Collection of 12-month follow-up questionnaires began in April 2004 and, to date, 38 of the expected 55 questionnaires have been collected. Telephone calls are placed on a regular basis to collect the remaining follow-up questionnaires.

BACKGROUND CHARACTERISTICS OF STUDY PARTICIPANTS

To date, 85 participants have completed baseline measures. The following section provides an update of the baseline statistics from last year's report which reflected only 65 participants. Sample characteristics from these preliminary data include: a mean age of 54 years (range 32-81 years), 94% Caucasian, 73% married or living with a partner, 88% have children, 26% have earned a college degree or higher, and 72% have an annual household income of $45,000 or greater. Approximately 42% of the sample have been

diagnosed with Stage 1 breast cancer and 27% have been diagnosed with Stage 2 breast cancer. With regard to treatment methods the majority of the sample (91%) received multiple treatment methods (lumpectomy and lymph node dissection 68%; lumpectomy, mastectomy, and dissection 8%; lumpectomy, dissection and radiation 14%; mastectomy and dissection 35%; mastectomy, dissection, and chemotherapy 18%). 52% of the lymph node dissections were sentinel node and 24% were axillary node. 9% of the sample received both a sentinel and axillary dissection.

Table 1: Patient Characteristics at Baseline

Patient Demographics (N = 85)		
Age, years (median (min, max)): 52 (32, 81)		
	N	**Percentage (%)**
Race		
White	69	81
Black	14	17
Asian	1	1
Missing/Refused	1	1
Ethnicity		
Hispanic or Latino	0	0
Non-Hispanic or Latino	80	94
Missing/Refused	5	6
Marital Status		
Single, never married	10	12
Married/Partnered	62	73
Separated	1	1
Divorced	6	7
Widowed	6	7
Education		
High School or Below	24	28
Vocational/Technical School	4	5
Undergraduate College/University	34	40
Graduate/Doctoral Degree	22	26
Treatment History		
Lumpectomy	60	71
Mastectomy	31	37
Lymph node dissection	81	95
Chemotherapy	36	42
Radiation	12	14

LYMPHEDEMA-RELATED KNOWLEDGE

At baseline, LE-related knowledge was low, with only 12% of the women answering the majority of questions (at least 17 out of 19) correctly. The mean knowledge score was 14 out of 19. At least 99% of the women were able to correctly identify that it is recommended to keep your LE affected arm very clean and well moisturized, 98% to

avoid blood pressure readings and injections on the affected arm, and 95% to wear gloves when doing housework or gardening. The questions most frequently answered incorrectly were related to LE-related symptoms ("An inflammation or infection in the affected arm is a sign of LE", 45% incorrect), BRCA treatment risk-related factors ("Breast cancer treatment increases your chances of developing LE", 25%; "Lymphedema can only occur within the first month following surgery for breast cancer", 39%), and frequently performed risk-related behaviors ("It is advisable that you wear a well-fitted bra with wire support", 47%; "It is acceptable to wear tight jewelry around the affected fingers or arm", 46%; "When manicuring your nails, it is recommended that you always cut the cuticle", 47%; and "It is recommended that you avoid traveling by air", 52%). Since early action to treat lymphedema is essential to managing this condition, a lack of awareness about typical symptoms and onset of lymphedema among this sample is concerning, and suggests a need for more effective patient education approaches regarding lymphedema risk. Following baseline assessment, all study participants were given an information booklet outlining lymphedema risk for breast cancer patients. Paired t-tests revealed a significant increase in levels of lymphedema knowledge at 6-months (mean = 17.2) compared with baseline (13.5) ($t = 7.40$, $df = 61$, $p<.01$).

Table 2: Lymphedema Related Knowledge at Baseline

Lymphedema Knowledge Items	N = 85
It is recommended that you keep your affected arm very clean and well moisturized	99% Correct
It is advisable to avoid blood pressure readings and injections on the affected arm	98% Correct
It is advisable that you always wear gloves when doing housework or gardening	95% Correct
An inflammation or infection in the affected arm is not a sign of lymphedema	45% Incorrect
Lymphedema can only occur within the first month following surgery for breast cancer	39% Incorrect
It is advisable to wear a well-fitted bra with wire support	47% Incorrect

ADHERENCE TO LYMPHEDEMA MINIMIZATION PRACTICES

Using a dichotomous yes/no item format, preliminary baseline data show that adherence to certain LE-risk minimization strategies is high, especially those that entail more passive acceptance strategies. Specifically, 79% of the women are not cutting the cuticles of their affected arm (i.e., arm associated with the surgery); 87% are keeping their affected arm very clean and well moisturized; 82% are avoiding heavy lifting and carrying handbags with over the shoulder straps; 94% are avoiding tight jewelry around the affected fingers or arms; 80% are avoiding exposing the affected arm to the sun; and 94% of the women are currently avoiding blood pressure readings and injections on the affected arm. However, 53% of the sample is not currently using an electric razor to

remove hair under their affected arm, 53% are not wearing gloves when doing housework or gardening, and 31% are not avoiding extreme temperature changes when bathing or washing dishes. These are three important, and rather routine, behaviors recommended to prevent LE that require more active strategies. Moreover, 20% report that they do not consult with the doctor if they have any slight increase of swelling in the affected arm, hand, fingers, or chest wall, possibly related to the participants' lack of awareness of lymphedema symptoms identified in the assessment of lymphedema-related knowledge. Paired t-tests revealed a significant increase in the number of preventive strategies practiced at 6-months ($\underline{M}$ = 10.1) compared with baseline ($\underline{M}$ = 9.3) ($t = 2.27$, $df = 61$, $p<.03$).

Table 3: Adherence to Lymphedema Minimization Practices at Baseline

Lymphedema-related Adherence Items	N = 85
Avoid cutting cuticles when manicuring your nails	79%
Keeping their affected arm very clean and moisturized	87%
Avoid wearing tight jewelry around the affected fingers and arms	94%
Currently avoid blood pressure readings and injections on the affected arm	94%
Currently using an electric razor to remove hair from underarms	47%
Wearing gloves when doing housework or gardening	47%

PSYCHOSOCIAL PROFILE OF STUDY PARTICIPANTS

Attentional Style

Mean scores for the Monitor-Blunter Style Scale (MBSS) are comparable to those found in related research (Mean monitoring score=9.03, SD=2.80; Mean blunting score=4.05, SD=2.16).

Risk Perceptions

Overall, participants tended to underestimate their risk of developing LE. Specifically, when asked to rate their risk for developing LE on a 5 point Likert-type scale ranging from 1 = "much lower than average" to 5 = "much higher than average", 86% of the sample reported that they were at an average to lower than average risk for developing LE, despite the fact that in all cases the lymph node surgery they received placed them at an increased risk in comparison to breast cancer patients who do not have lymph node dissection or radiation. Moreover, of the women sampled who had received axillary node dissection, a treatment associated with an even higher risk for LE than sentinel surgery, 70% reported that they had an average to below average risk for LE despite the higher risk for LE development associated with this type of surgery. The actual risk of

developing LE following axillary lymph node dissection increases to 38% to 56% when adjuvant radiation is provided, however no participants to date have had this treatment combination. There were no changes in perceptions of lymphedema risk from baseline to 6-months.

Expectancies

With respect to outcome related expectations, using a 5 point Likert-type scale ranging from 1="not at all" to 5="very much", a subset of women endorsed the statements that LE is a serious condition (i.e., 32% "quite a bit"; 51% "very much"), that developing LE would interfere with their lives (i.e., 45% "quite a bit"; 28% "very much"), and that LE-related problems would last a long time (i.e., 32% "quite a bit"; 24% "very much"). A majority of the women endorsed a belief that there are measures they can take to prevent LE (i.e., 48% "quite a bit"; 14% "very much") and that practicing the recommended hand and arm procedures will minimize their chances of developing LE (i.e., 42% "quite a bit"; 31% "very much").

With regard to self-efficacy expectations, using the same Likert-type scale, a majority of the sample indicated that they did "not at all" believe that whether or not they developed LE was God's will (49%) or that the development of LE is just luck (47%), implying that they did not take a fatalistic view of LE development. A majority of the sample were certain that they can effectively adhere to recommended procedures to minimize LE risk (i.e., 46% "quite a bit"; 25% "very much") and that they will be regularly checking themselves for signs of LE (i.e., 34% "quite a bit"; 22% "very much"). The data indicate that although a majority of the women have positive expectations regarding LE preventive actions and a belief in their ability to carry them out, there is a large subset of individuals for whom this may not be the case. No differences in lymphedema-related expectancies and beliefs were reported from baseline to 6-month follow-up.

Table 4: LE- Related Expectancies at Baseline N=85

	Not at all (%)	A little bit (%)	Somewhat (%)	Quite a bit (%)	Very much (%)
Do you believe that LE is a serious condition?	0	4	13	32	51
Do you believe that LE would interfere with life?	1	2	24	45	28
Do you believe LE-related problems would last a long time?	1	8	35	32	24
Do you believe practicing the recommended arm and hand precautions will minimize your chances of developing Lymphedema?	2	4	20	42	31
Do you believe that whether or not you develop lymphedema is god's will?	49	12	20	7	12
To what extent do you believe that you can effectively adhere to recommended arm and hand procedures to minimize lymphedema risk?	1	5	23	46	25

Distress

As measured by the Revised Impact of Events Scale (RIES), participants reported low to low-moderate LE risk-related distress, as defined by the presence of intrusive and avoidant risk-related ideation (Mean intrusion scale score=3.25, SD=5.08; Mean avoidance scale score=5.63, SD=7.67). There were no significant differences in levels of intrusive and avoidant ideation from baseline to 6-months.

Using a 5-point Likert-type scale ranging from 1="not at all" to 5="very much", women were asked to rate their LE-risk related affect. Overall, women reported low levels of risk-related affect. Specifically, a majority of women endorsed "not at all" or "a little bit" when asked if they were experiencing thoughts of LE that affected their mood or ability to perform daily activities (mood: 56% "not at all", 24% "a little bit"; ability to perform daily activities: 67% "not at all", 20% "a little bit"), or the experience of LE-risk related worry (34% "not at all", 45% "a little bit"), sadness/depression (44% "not at all", 34% "a little bit"), scared/anxious (39% "not at all", 38% "a little bit"), or anger (65% "not at all", 18% "a little bit"). However, despite this tendency to manage LE-risk related emotions, there is a subset of women for whom risk related affect was more present. For example, there is a group of women who endorse "somewhat", "quite a bit", or "very much" when asked if they have LE-related thoughts that have affected their mood (6% "somewhat", 13% "quite a bit") or daily activities (7% "somewhat", 5% "quite a bit", 1% "very much"), or feel worried (8% "somewhat", 9% "quite a bit", 4% "very much"), sad/depressed (13% "somewhat", 6% "quite a bit", 4% "very much), scared/anxious (13% "somewhat", 6% "quite a bit", 5% "very much"), or angry (12% "somewhat", 1% "quite a bit", 5% "very much") regarding their LE risk. Moreover, a number of women report that they are "somewhat" (25%), "quite a bit" (11%), or "very much" (1%) worried about knowing when to contact the doctor about any LE symptoms they experience.

Paired t-tests revealed significant decreases in levels of lymphedema-related ability to perform daily activities from baseline (mean =1.61) to 6-months later (mean=1.24) [t = -2.68, df = 61, p<.01]; feelings of sadness or depression in relation to lymphedema risk (baseline = 1.95; 6-months = 1.54)[t = -2.21, df = 60, p<.03]; and feeling scared/anxious regarding lymphedema risk (baseline = 1.95; 6-months = 1.54) [t = -2.25, df = 61, p<.03]. In addition, compared with baseline, at 6-months participants reported fewer cases of feeling worried about knowing when to contact the doctor about LE symptoms (baseline = 2.05; b-months = 1.540) [t = -2.52, df = 60, p<.03].

Table 5: LE-Related Distress at Baseline N = 85

	Not at all (%)	A little bit (%)	*Somewhat* (%)	Quite a bit (%)	Very much (%)
How after have thought about Lymphedema affected your mood?	56	24	6	13	0
How often have thought about Lymphedema affected your ability to perform your daily activities?	67	20	7	5	1
Have you been worried about you risk for lymphedema?	34	45	8	9	4
Have you felt sad or depressed when thinking about your risk for lymphedema?	44	34	13	6	4

Values and Goals

Overall, women reported placing a large degree of value on their physical appearance and physical functioning. Using a 5-point Likert-scale ranging from "not at all" to "very much," the entire sample reported "functioning well" to be "quite a bit" (13%) to "very much" (85%) important to them. Similarly, the entire sample reported "feeling well" to be "quite a bit" (15%) to "very much" (84%) important to them. In addition, the majority of the sample reported the following to be "quite a bit" to "very much" important to them: the way in which they perceive their own bodies (47% and 32%, respectively), feeling attractive (34% and 34%, respectively). Eight-eight percent of the baseline sample reports the way in which their partner perceives their body to be "somewhat" (26%), "quite a bit" (42%), or "very much" (20%) important to them.

Table 6: LE-Related Values and Goals N=85

	Not at all (%)	A little bit (%)	*Somewhat* (%)	Quite a bit (%)	Very much (%)
Importance of functioning well?	0	0	1	13	85
Importance of feeling well?	0	0	1	15	84
To what extent is the way you perceive your body important to you?	0	1	20	47	32
To what extent is the way your partner perceives your body important to you?	2	2	26	42	20

Self-Regulatory Strategies

Using a 5-point Likert-type scale ranging from 1 = "not at all" to 5 = "very much", women were asked to rate their ability to manage LE-related thoughts and strategic plans to reduce their risk of developing LE. Overall, women reported a positive sense of control over their ability to manage LE-related feelings and the behaviors in which they were able to engage. Specifically, the majority of the sample felt that they were "quite a bit" (39%) to "very much" (41%) able to make the necessary lifestyle changes in order to carry out recommended LE minimization precautions and that they were "quite a bit" (41%) to "very much" (37%) able to follow the recommended behaviors that may minimize LE symptoms. A majority of the sample felt that they are "quite a bit" (34%) to "very much" (37%) able to limit the amount of stress they experience when they perform the recommended symptom minimization practices, that they are "quite a bit" (33%) to "very much" (28%) able to limit the amount of stress they experience about their LE risk, and that they are "quite a bit" (29%) to "very much" (29%) able to calm themselves down when they experience anxiety or worry about developing LE. Paired t-tests revealed a significant increase in self-regulatory skills from baseline to 6-months with participants reporting being better able to calm down when feeling anxious about lymphedema risk (baseline = 3.71; 6-months = 4.18)[$t = 2.43$, $df = 55$, $p<.02$].

Table 7: LE-Related Self-Regulatory Strategies N=85

	Not at all (%)	A little bit (%)	*Somewhat* (%)	Quite a bit (%)	Very much (%)
I am able to limit the amount of stress I experience about my lymphedema risk.	2	6	31	33	28
I am able to make necessary lifestyle changes to carry out recommended precautions to minimize lymphedema symptoms?	2	4	14	39	41

KEY RESEARCH ACCOMPLISHMENTS

- 85 new participants have completed baseline measures since August 2003. Sixty-two 6-month follow-up questionnaires and 38 12-month follow-up questionnaires have been collected since August 2003.
- Members of the research team have regularly accessed the FCCC electronic Soarian Clinical Access Database to identify new patients attending the Breast Evaluation Clinic at either site. Potential participants are FCCC patients who are initiating their breast cancer treatment or women who have come to FCCC for an initial consultation or post-diagnosis/pre-treatment second opinion.
- Potentially eligible women were tracked on a regular basis until their full eligibility (i.e., cancer stage, post-surgery status, receiving treatment at FCCC) can be determined. Eligible patients are contacted by telephone to solicit participation in the study after their medical records indicate that they have completed their surgery.
- Members of the research team continue to enter data from all study questionnaires as they are collected.
- The research team maintains an Access database to track participant follow-up. After a participant completes the baseline survey they are entered into the Access database and monitored to coordinate their follow-up interview date.
- The FCCC IRB audited this study in February 2005 and found it to be in accordance with compliance regulations.

REPORTABLE OUTCOMES

We have compiled 5 papers that analyze literature on adherence and adjustment in breast cancer disease/risk context and integrated findings obtained with our guiding theoretical model.

- Miller, S.M. & Sherman, K.A. (2004). Cancer screening. In N. Anderson (Ed.) The Encyclopedia of Health and Behavior. CA: Sage Publications.

- Miller, S.M., Bowen, D. J., Campbell, M.K., Diefenbach, M.A., Gritz, E.R., Jacobsen, P.B., Stefanek, M., Fang, C.Y., Lazovich, D., Sherman, K.A., Wang, C. (2004). Current research promises and challenges in behavioral oncology: Report from the American Society of Preventive Oncology Annual Meeting. Cancer Epidemiology, Biomarkers and Prevention, 13, 171-180.
- Miller, S.M., Fleisher, L., Roussi, P., Buzaglo, J.S., Schnoll, R.A., Slater, E., Rayser, & Popa-Mabe, M. (2005) Facilitating informed decision making about breast cancer risk and genetic counseling among women calling the NCI's Cancer Information Service. Journal of Health Communication, Special Issue on Health Communication.

- Miller, S.M., Roussi, P., Daly, M.B., Buzaglo, J.S., Sherman, K.A., Godwin, A.K., Balshem, A., & Atchison, M.A. (in press) Enhanced counseling for women undergoing BRCA1/2 testing: Impact on

making about risk prevention behaviors. Health Education and Behavior, Special Issue on Genetic Risk. In press.

- Sherman, K.A., Miller, S.M., Gorin, S.S., et al. Psychosocial determinants of participation. Psychosocial determinants of participation in breast cancer risk counseling programs and screening regimens among African-American women. NY: Susan G. Komen Foundation and African American National Advisory Committee, In press.

- We are also preparing three volumes that will integrate our ongoing study with the larger field of behavior and oncology.

  - Miller, S.M., McDaniel, S., Rolland, J., & Feetham, S. (Eds.) Individuals, families, and the new genetics. New York: Norton Publications, in press.

  - Miller, S.M., Bowen, D., Croyle, R. & Rowland, J. (Eds.) Handbook of psychosocial approaches to cancer prevention. Washington, D.C.: American Psychological Association, in preparation.

  - Elk, R., Miller, S.M., & Daly, M.B. Cancer and the Ashkenazi Jewish Woman. McGraw-Hill Publications, in press.

CONFERENCE PRESENTATIONS AND DISTINGUISHED VISITORSHIPS

Miller, S.M., Fleisher, L., Rodoletz, M., Buzaglo, J.S., Glenn, M., Higman, S., Cornfeld, M., Schnoll, R.A., Balshem, A., & Engstrom, P.F. Implementation of a Worksite Cancer Control Program: Enhancing Cancer Prevention-related Intentions and Attitudes Among Worksite Employees. Paper presented at Translating Research Into Practice (TRIP): Advancing Excellence from Discovery to Delivery, Symposium on Innovation in TRIP for Prevention, Washington, D.C., July, 2004.

Miller, S. M. 8th International Congress of Behavioral Medicine. Paper on: Tailoring Monitoring vs. blunting in the preparation for stressful medical procedures. Part of Invited Symposium on: Psychological Preparation for Medical Intervention. Mainz, Germany. August, 2004.

Miller, S.M. University of Michigan School of Public Health. Invited Speaker on: Facilitating Risk Processing in at-risk populations as part of Symposium on The Challenge Ahead: Implications of Genomic Information in Public Health Education and Behavior Change. Ann Arbor, MI, October, 2004.

Miller, S.M. 29th Annual Meeting of the American Society of Preventive Oncology, San Francisco, CA. March, 2005.

Miller, S.M., Sponsored by American Associates, Ben-Gurion University, Philadelphia Chapter, and Fox Chase Cancer Center. Invited speaker on: Fighting Breast Cancer March , 2005.

Miller, S.M. Invited Speaker on: A Developmental Perspective Cancer Risk and Responses. University of the Sacred Heart, Tokyo, Japan, March 2005.

Miller, S.M. Invited Speaker: Psychosocial Factors in Cancer. Choju Medical Research Center, Mie, Japan, March, 2005.

Miller, S.M., Chair, Invited Symposium and Roundtable Session on Decision Making in the Cancer Context – Translation from Basic Science through Population Health. Annual Meeting of the Society of Behavioral Medicine. Boston, MA. April, 2005.

Miller, S.M. Invited Colloquium on Coping with Cancer Risk and Disease: Is There a Role for Behavioral Science? Sponsored by Case Western Comprehensive Cancer Center, Case Western Reserve University, Cleveland, OH. April 29, 2005.

Miller, S.M. University of Padova (sponsored by the Department of Pediatrics). Invited Speaker on Monitoring vs. Blunting Styles of Coping: To See or Not to See?, Padova, Italy, May 2005.

Miller, S.M. Invited Speaker, Presented as part of Invited Symposium on Educating Women about Risk Counseling/Genetic Testing Makes a Difference in Intended Use of Services, Especially among those at High-Risk: Results of a Randomized Trial Among Callers to the Cancer Information Service. The Department of Defense (DOD) Fourth Era of Hope Meeting, Philadelphia, PA, June, 2005.

Miller, S.M. Invited Co-Chair, Invited Symposium on People and Populations. The Department of Defense(DOD) Fourth Era of Hope Meeting, Philadelphia, PA, June, 2005.

Miller, S.M. Invited Speaker on Tailored Communication to Enhance Adaptation across the Breast Cancer Spectrum. Presented as part of Invited Symposium on Behavioral Centers of Excellence: Treating More Than the Tumor. The Department of Defense (DOD) Fourth Era of Hope Meeting, Philadelphia, PA, June, 2005.

Miller, S.M. Invited Speaker. Stress and Anxiety Research Society (STAR). Crete, July, 2006.

CONCLUSIONS

Although the number of participants continues to be lower than anticipated because of temporary staffing shortages, we have trained new staff in recruitment procedures in order to increase the number of participants screened for eligibility and recruited. Thus, an additional 12-months of continuous recruitment efforts would greatly increase accrual

rates. As recruitment continues, we anticipate no further obstacles in conducting our study as scheduled, and we expect no additional delays in the progress of this project.

Descriptive data continue to indicate that there is a need for increased LE education and improved adherence to LE-related behaviors. Although a number of women are aware of LE minimization practices and their potential benefits, preliminary data suggest that they are not incorporating all of the recommendations into their daily lives, especially those that may constitute active strategies. Additionally, preliminary descriptive data analysis shows a significant correlation between high monitoring styles with more accurate knowledge of lymphedema risk factors (e.g. knowledge of the fact that women who have axillary node surgery followed by radiation therapy have higher risk of developing lymphedema compared to no radiation therapy). Moreover, our early data suggest that promoting the maintenance of LE preventive/minimization behaviors and enhancing the management of LE risk-related emotions over time may be a worthwhile focus for a subset of individuals. Taken together, our preliminary findings support the importance of this study in increasing LE-related knowledge and improving health behaviors to reduce women's risk for developing LE.

This research will fill a void in the breast cancer literature with respect to lymphedema. Survivors of breast cancer need to attend to the types of precautionary measures they can employ to prevent and control the occurrence of symptoms. However, little is known about how individuals understand and make sense of these issues, and few resources have been developed to address this problem. Hence, it is important to explore the psychosocial factors that facilitate or undermine the uptake of preventive behaviors, as well as their sustained maintenance over time.

Through more systematic investigation of these factors, we will be able to develop a profile of the role of cognitive-emotional processing in the management of lymphedema. These data will ultimately be used to design and evaluate enhanced management protocols, tailored to the individual's cognitive-emotional signature.

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Suzanne M. Miller, Ph.D.

Senior Member, Division of Population Science

Director, Psychosocial and Behavioral Medicine

Fox Chase Cancer Center

7701 Burholme Ave

Philadelphia PA 19111

USA

Phone: 215 728 4069

Email: sm_miller@fccc.edu

Kerry A. Sherman, Ph.D.

Assistant Member

Psychosocial and Behavioral Medicine

Fox Chase Cancer Center

510 Township Line Road, 3rd floor

Cheltenham, PA 19012

USA

Phone: 215 214 1645

Fax: 215 728 3056

Email: ka_sherman@fccc.edu

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CANCER SCREENING

The Role of Screening Regimens in Cancer

Cancer is evident in virtually every country of the world, with developed countries having a greater incidence of disease than non-developed countries. The American Cancer Society reports that in the United States alone, cancer accounts for one in four deaths every year, with mortality rates being disproportionately high among ethnic minority populations. The aim of screening is to detect the presence of disease in asymptomatic individuals, thus managing the disease at a more treatable stage. Cancer mortality rates in this country have been considerably reduced with the advent of effective early detection screening regimens, notably mammography for women 50 years and older (breast cancer), Pap smears (cervical cancer), and fecal occult blood testing (FOBT; colorectal cancer). These types of established screening guidelines have frequently been implemented after extensive debate regarding whether screening would prolong life among specific populations (e.g., mammography in women under 50 years of age). Currently, the utility of a number of other procedures is under investigation, including prostate specific antigen (PSA; prostate cancer), CA125 and transvaginal ultrasound (ovarian cancer), flexible sigmoidoscopy and colonoscopy (colorectal cancer), and spiral computed tomography (CT; lung cancer). While the ultimate utility of screening is unclear, it remains the only feasible and recommended population-based approach for early cancer detection.

Effective screening calls for long-term adherence to recommended guidelines over the lifecycle. However, there are a number of extrinsic and intrinsic factors that influence cancer screening behaviors and may serve as barriers to sustained adherence. From the extrinsic perspective, access to care is the major determinant of screening attendance, particularly among low-income, ethnic minority, elderly, and rural populations. Inadequate or no healthcare insurance, geographic isolation, lack of transportation and childcare, and availability of medical interpretation services for non-English speaking individuals are important barriers to care. A number of intervention approaches have been implemented that directly address access-related barriers to screening attendance. Programs that improve access to screening facilities (e.g., mobile screening services, provision of childcare assistance, transportation to screening units), minimize language barriers, and provide culturally sensitive services have proven effective in enhancing screening utilization.

However, while interventions to enhance access have been shown to improve screening adherence, in many cases the barriers to adherence are also centrally related to factors intrinsic to the individual, namely psychosocial factors, particularly over the long term. We now review the psychosocial factors influencing screening adherence and discuss the importance of targeted

psychosocial intervention protocols, tailored to assess and address these barriers, in promoting sustained screening adherence.

Psychological Factors Influencing Screening Adherence

The Cognitive-Social Health Information Processing (C-SHIP) model provides a framework for understanding the cognitive, emotional, and social factors that influence cancer screening behaviors. According to the cognitive-social model, key determinants of cancer screening behaviors include the individual's: 1) cancer-related knowledge and perceptions of cancer vulnerability; 2) expectancies and beliefs about cancer risk and available courses of action; 3) health-related values and goals; 4) cancer-related distress; and, 5) coping skills for managing distress and generating action plans for adherence to screening and follow-up health-protective behaviors.

Cancer-related Knowledge and Risk Perceptions

Reluctance to participate in cancer screening programs is related, first and foremost, to lack of cancer awareness. Lack of knowledge about the etiology of cancer and available screening options is widespread among both average- and high-risk populations. Groups showing particularly low rates of cancer screening, including lower income, less educated, rural, and inadequately insured individuals

(such as Native Americans, African Americans, Hispanics, the elderly), show particularly low levels of cancer-related knowledge.

Inaccuracies in knowledge are associated with misperceptions about one's cancer risk. Studies show that some individuals consistently underestimate their risk for cancer, while others overestimate their risk. Further, subjective risk perceptions tend to vary with cancer type. In particular, men at risk for prostate cancer tend to underestimate their risk, whereas women at risk for breast cancer tend to overestimate their risk. Risk perceptions also vary according to the way in which they are measured (e.g., as an estimate of the percentage lifetime likelihood of developing cancer, ranging from 0% to 100%; or as a Likert scale ranging from very low likelihood of developing the disease to very high). Not surprisingly, subjective risk levels show a poor correlation with objective risk levels.

Cancer-related Expectancies and Beliefs

Perceived benefits (i.e., pros) and limitations (i.e., cons) about cancer screening are associated with adherence. When the expected pros of cancer screening are emphasized (as when the physician recommends the screening procedure), participation rates are increased. Hence, screening rates are higher (although still less than optimal) in cases where there are clear consensus guidelines (e.g., mammography, Pap smear, and FOBT), and lower where

consensus guidelines are not clearly established (e.g., PSA for prostate cancer, skin cancer screening). In addition, ambivalent attitudes towards screening utilization among providers and consumers tend to act as barriers to adherence, and may relate to the public debates that have taken place about the efficacy of these procedures. Rates of adherence may also depend on the individual's level of objective cancer risk, such that increased risk leads to increased screening utilization, most likely as a result of greater physician advice.

Conversely, perceived barriers (e.g., negative beliefs about the efficacy or aversiveness of the diagnostic procedure) have been consistently associated with reduced screening adherence. For example, screening adherence rates are lower in cases where the procedures are either unpleasant or associated with discomfort (e.g., FOBT, sigmoidoscopy and colonoscopy for colorectal cancer screening). A related expectancy factor, perceived lack of confidence to perform the procedure, is also associated with low levels of screening adherence, particularly in the case of self-examination procedures that require the individual to personally execute the behavior (e.g., skin self-examination and breast self-examination).

Interestingly, cancer screening and diagnostic follow-up adherence among elderly individuals is considerably lower than for their younger counterparts. Given that the efficacy of widely-used screening methods, such as

mammography, has not yet been determined for individuals over the age of 65, uncertainty about the efficacy of cancer screening among physicians and patients may contribute to lower adherence among this age group.

Cancer-related Values and Goals

Cancer-related values include fatalistic beliefs (i.e., believing, for instance, that there is no use in getting screened, since cancer is inevitable). These types of beliefs are prevalent among ethnic minorities, particularly those who are lower income, less well educated, and unemployed. Individuals with greater fatalistic beliefs report significantly lower levels of adherence to cancer screening. Further, culturally specific values associated with shame, preferences for non-Western medicine, and mistrust of health professionals have been identified as barriers to cancer screening adherence. These types of shared cultural values tend to reduce expectations about the utility of cancer screening, thereby reducing the motivation for an individual to adhere to these recommendations over the long term.

Certain shared cultural values appear to have a beneficial effect on cancer screening behaviors. Joan Bloom, from University of California, reports that family members can support screening behaviors by acting as a cultural symbol of the reason to stay healthy. The family's support of the individual's attempts to maintain recommended cancer screening regimens is especially important among

cultures placing a high value on interdependence, and most evident for initial cancer screening and highly invasive tests (e.g., sigmoidoscopy). Thus, appealing to family membership may be an effective means of facilitating cancer screening adherence among highly interdependent families, particularly in the case of unfamiliar or uncomfortable tests.

Media exposure represents an additional factor likely to directly influence shared screening-related values and goals and, hence, screening adherence. Breast and cervical cancer screening (which are associated with better adherence) have received a high degree of media attention over the last few decades, but colorectal cancer screening (which is associated with poorer adherence) has received little publicity.

Cancer-related Distress

Cancer-related distress refers to the situation-specific (i.e., state) anxiety, worry, and intrusive thoughts that may arise in response to a cancer threat. The effect of cancer-related distress on screening adherence differs according to the level of distress experienced. In the case of low levels of worry, cancer-related concerns are not activated, so there is no motivation for initiating and sustaining screening behaviors. For example, low levels of cancer worry among the elderly, who tend to believe they are no longer vulnerable to cancer, have been linked

with poor screening adherence. In contrast, in the case of high levels of worry, excessive anxiety activates avoidance that can undermine the individual's intentions to adhere to recommended screening regimens. For example, among ethnic minorities, fear of cancer is reported as one of the most important reasons for not participating in screening programs and for not attending diagnostic-follow-up (e.g., colorectal, cervical). Fear of the procedure itself also undermines screening and follow-up diagnostic adherence, particularly concerns and fears about the iatrogenic effects of biopsies and repeat x-rays among individuals recalled for further diagnostic investigations.

Research by Suzanne Miller and colleagues at Fox Chase Cancer Center in a number of cancer-risk contexts indicates that individuals need to be made sufficiently aware of the cancer threat to motivate them to participate in screening regimens, but should not become so anxious that they actively avoid screening participation. Fear of cancer should also be contained so that it does not lead to over-use of screening, as in the case of excessive performance of breast cancer self-examination that is sometimes found among high-risk women.

Cancer-related Self-Regulatory Skills

To effectively adhere to cancer screening regimens, individuals must be able to manage cancer risk-related distress and to develop specific action plans for

carrying out health-related behaviors (e.g., scheduling an annual cancer screening examination). Individuals who are adherent to one form of cancer screening, and who generally enact health-protective behaviors (e.g., exercise, healthy eating, cholesterol check), appear to be more likely to participate in other forms of cancer screening. This pattern suggests that the individual has available a general set of self-regulatory skills for managing cancer- and disease-related distress and for executing effective action scripts for maintaining recommended health-protective behaviors.

Consistent with this analysis, screening adherence is influenced by the type of procedure: i.e., medical examination regimen vs. self-examination regimen. Medical examination is carried out by medical practitioners, and includes direct observation (e.g., skin, cervix), palpation for detecting lumps or tumors (e.g., breast, prostate, rectum) and procedures such as endoscopy, x-rays, magnetic resonance imaging, or ultrasound for internal cancers (e.g., stomach, colorectal). In contrast, self-examination is performed by the individual and includes direct observation (e.g., skin cancer check) and palpation (e.g., breast self-examination).

For individuals to effectively carry out self-examination procedures, they must have in place strategies for managing cancer risk-related distress and for

developing specific action plans for carrying out the required health-related behaviors. Not surprisingly, adherence rates are highest for procedures that are based solely on medical examination procedures (e.g., Pap smear and mammography), and thereby require relatively fewer self-regulatory skills. In contrast, rates are lowest for procedures that require the individual to enact and sustain the behavior (e.g., for colon cancer, since the individual must collect three separate fecal specimens for laboratory analysis). This differential pattern of adherence is also evident within a particular cancer type. For example, adherence to mammography and clinical breast examination (procedures conducted by a medical professional) far exceed adherence rates to breast self-examination (a self-initiated screening procedure).

Psychosocial Interventions to Facilitate Cancer Screening Adherence

In sum, the effectiveness of cancer screening regimens rests upon long-term adherence. However, even among well-established cancer screening regimens (e.g., breast, cervical), adherence is less than ideal. Effective screening adherence requires that individuals be knowledgeable about their cancer screening options, believe that the pros of cancer screening outweigh the cons, have values consistent with the belief that cancer screening is a useful tool for reducing cancer mortality, and have a moderate level of cancer-related distress and perceived vulnerability, sufficient to maintain (but not overwhelm) self-regulatory strategies

for long-term adherence. In addition to improving access to care, these psychosocial factors need to be taken into account in a coordinated fashion when designing interventions to promote performance of cancer screening behaviors.

The most effective intervention protocols are those that are carefully targeted to the specific audience (e.g., ethnic or cultural group), and systematically tailored to the individual's profile of cognitions and affects that become activated in the processing of cancer-relevant information. The use of preparatory counseling strategies that assess and address cognitive-affective barriers to diagnostic follow-up adherence has been found to be beneficial in enhancing participation in several cancer screening contexts (e.g., prostate, cervical, breast). For example, research conducted by Suzanne Miller and colleagues has explored the utility of a tailored pre-appointment telephone counseling intervention, targeted to low-income minority women who need to undergo diagnostic follow-up following notification of an abnormal Pap smear. The counseling intervention addressed the individual's cognitive (i.e., inadequate knowledge; misperceptions of risk; inaccurate expectancies); affective (i.e., distress levels; anticipated discomfort); and self-regulatory (i.e., poor planning) barriers to adherence. Patients who received telephone counseling displayed significantly higher adherence rates to the initial follow-up screening appointment after feedback of the abnormal test result, in comparison with patients who

received a telephone appointment reminder call and in comparison with usual care. Further, the effects of the intervention were not only evident in the short-term, but were also sustained over the long-term (i.e., at the 6-month follow-up screening appointment). In addition to traditional counseling approaches (e.g., telephone counseling, print materials), recent technological developments will allow for the development of especially promising innovative approaches to enhancing screening adherence, through the use of new media approaches (e.g., interactive internet- and CD-Rom-based interventions).

A key factor that needs to be considered when designing intervention protocols is the role of stable, pre-existing individual differences in the pattern of response to health-related information. According to the cognitive-social model, individuals are characterized by distinctive cognitive-affective signatures that determine their characteristic profile of responses to cancer risk feedback. High monitors (who typically attend to and scan for health-related messages) are more likely to respond to health threats with heightened perceptions of their own vulnerability, greater risk-related distress, and poorer management of anxiety. In contrast, low monitors (who distract from and ignore health-related messages) are more likely to demonstrate inadequate cancer-related knowledge, lowered risk perceptions, and poor planning. These two response styles have implications for the design of tailored counseling and communication messages. High monitors

fare better with voluminous information that reduces uncertainty, promotes reassurance, and manages risk-related distress. Low monitors, on the other hand, benefit most from interventions that increase the salience of threat and provide cues and prompts for action.

Summary

Despite recent technological advances in cancer control, adherence to available cancer screening regimens continues to fall below optimal levels. Barriers to adherence include lack of access to care, cognitive factors (i.e., cancer-related knowledge, perceived vulnerability, expectancies and beliefs about cancer risk and available courses of action), social factors (i.e., cancer-related values and goals), and affective factors (i.e., cancer-related distress and self-regulatory strategies to manage distress and to execute effective action scripts for maintaining screening recommendations over the long-term). Psychosocial interventions carefully targeted to the population group, and tailored to the unique cognitive-affective profile and response style of the individual, in combination with access-enhancing approaches, appear most promising.

Suzanne M. Miller, Ph.D.

Senior Member, Division of Population Science

Director, Psychosocial and Behavioral Medicine

Fox Chase Cancer Center

7701 Burholme Ave

Philadelphia PA 19111

USA

Phone: 215 728 4069

Email: sm_miller@fccc.edu

Kerry A. Sherman, Ph.D.

Assistant Member

Psychosocial and Behavioral Medicine

Fox Chase Cancer Center

510 Township Line Road, 3rd floor

Cheltenham, PA 19012

USA

Phone: 215 214 1645

Fax: 215 728 3056

Email: ka_sherman@fccc.edu

See also: **Psychosocial Aspects of Cancer**

Psychosocial Treatment of Cancer

Prevention of Cancer

Adherence

Further readings:

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Meeting Report

Current Research Promises and Challenges in Behavioral Oncology: Report from the American Society of Preventive Oncology Annual Meeting, 2002

Suzanne M. Miller,[1] Deborah J. Bowen,[2] Marci K. Campbell,[8] Michael A. Diefenbach,[1] Ellen R. Gritz,[3] Paul B. Jacobsen,[4] Michael Stefanek,[5] Carolyn Y. Fang,[1] DeAnn Lazovich,[7] Kerry A. Sherman,[1] and Catharine Wang[6]

[1]Fox Chase Cancer Center, Philadelphia, Pennsylvania; [2]Fred Hutchinson Cancer Center; [3]The University of Texas M. D. Anderson Cancer Center; [4]Moffit Cancer Center; [5]National Cancer Institute; [6]University of Michigan; [7]University of Minnesota; and [8]University of North Carolina

Abstract

The Behavioral Oncology Interest Group of the American Society of Preventive Oncology held a Roundtable session on March 10, 2002, at the American Society of Preventive Oncology annual meeting in Bethesda, Maryland, to discuss the current state-of-the-science in behavioral approaches to cancer prevention and control and to delineate priorities for additional research. Four key areas were considered: (*a*) behavioral approaches to cancer genetic risk assessment and testing; (*b*) biological mechanisms of psychosocial effects on cancer; (*c*) the role of risk perceptions in cancer screening adherence; and (*d*) the impact of tailored and targeted interventions on cancer prevention and control research. The evidence reviewed indicates that behavioral approaches have made significant contributions to cancer prevention and control research. At the same time, there is a need to more closely link future investigations to the underlying base of behavioral science principles and paradigms that guide them. To successfully bridge the gap between the availability of effective new cancer prevention and control technologies and the participants they are meant to serve will require the development of more integrative conceptual models, the incorporation of more rigorous methodological designs, and more precise identification of the individual and group characteristics of the groups under study.

Introduction

Behavior has been shown to play a key role in many aspects of cancer prevention and control from disease risk through treatment through survivorship. Indeed, behavioral science has emerged as one of the key priorities at the National Cancer Institute and a rapidly growing area for funded research (1). Yet, behavioral science is not always well integrated with other research areas; for example, behavioral research is often not coordinated with the clinical research agenda of the nation's cancer centers and investigations. In 2000, we therefore established a Behavioral Oncology Interest Group, nested within the existing umbrella organization of the American Society of Preventive Oncology. To date, the Behavioral Oncology Interest Group Steering Committee, comprised of behavioral scientists, has brought together a group of ~200 investigators who all share ongoing interests and active research programs at the interface of behavioral science and oncology. The mission of this group is to provide a structured forum for behavioral interactions and collaborations, with a view to addressing basic unresolved issues in psychosocial assessment and intervention approaches to cancer prevention and control.

To further this mission, we arranged a preconference session at the March 2002 meeting of American Society of Preventive Oncology, held in Bethesda, Maryland, with the goal of conducting a state-of-the-science evaluation of current areas of research focus in behavioral oncology. Four areas of research interest were chosen by the Behavioral Oncology Steering Group via a series of telephone conference calls before the annual meeting. These areas were as follows: (*a*) behavioral approaches to cancer genetic risk assessment and testing; (*b*) biological mechanisms of psychosocial effects on cancer; (*c*) the role of risk perceptions on cancer screening adherence; and (*d*) the impact of tailored and targeted interventions on cancer prevention and control research. The four topics were judged to be sufficiently well established in the behavioral oncology field to have generated an impressive and tantalizing array of research findings. The overarching goal of the roundtables was to provide an overview of what is known, what is suspected, and what is still unknown or unexplained to delineate priorities for research concentration and collaboration.

Two behavioral science leaders were selected to lead each roundtable based on their expertise in the field. One recorder supported the work of each roundtable. Discussions lasted on average one and one-half hours and were tape recorded. Participants were comprised mainly of behavioral scientists and self-selected into a roundtable based on interest and/or expertise. The specific objective of each roundtable was to summarize the current state of the field and to recommend potential directions and areas for future research. In this article, we highlight the key conclusions of the four roundtable discussions. For each topic area, we present the conclusions in terms of: (*a*) key findings and goals of the research area; (*b*) strengths of the research area; (*c*) weaknesses of the research area; and (*d*) directions for future research.

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Requests for reprints: Deborah J. Bowen, Fox Chase Cancer Center, 7701 Burholme Avenue, Philadelphia, PA 19111. Phone: (215) 728-4069; Fax: (215) 728-3056; E-mail: SM_Miller@fccc.edu.

Behavioral Oncology Roundtable 1: Behavioral Approaches to Cancer Genetic Risk Assessment and Testing

Introduction. The development and clinical use of genetic mutation testing for cancer risk has provided unprecedented opportunities for a new area of research: the behavioral and psychological antecedents and consequences of genetic risk assessment and testing. Although genetic testing has been used medically in prenatal settings and in the identification of risk for various diseases such as Huntington's disease (2), the incorporation of genetic risk information into the field of cancer prevention and control is relatively new.

Key Findings and Goals of the Research Area. One of the main research goals has been to design effective methods of providing support to individuals undergoing genetic mutation testing. In-person genetic counseling has been the main focus of research to date. Other methods such as telephone, CD-ROM, and web-based modalities are beginning to be evaluated (3–6). The model of genetic counseling for cancer susceptibility was adapted from the prenatal genetic counseling field and modified to be more relevant for a chronic disease setting. Testing for *BRCA1/2* genetic mutations has been a main cancer model for mutation testing, but others such as testing for colon cancer mutations have also received research attention as well. (*e.g.*, Refs. 8–12). The focus has generally been on screening/testing rates among genetically high risk patients (13), effects of genetic counseling and testing participation on short- and long-term psychosocial functioning (14, 15), and psychological variables that predict reactions to testing and the sequelae of testing (14, 15). With the identification of these variables, the design of counseling interventions that are tailored to the individual's needs and issues has become a focus of research (16, 17).

In addition to facilitating decision-making regarding initial testing, the patterns and factors that determine subsequent decisions about the uptake of surveillance (*e.g.*, mammography or ovarian ultrasound) and preventive (*e.g.*, chemoprevention or prophylactic surgery) regimens are a developing focus in this area (18, 19). An additional, but similarly less well researched, goal is to identify the effects of the testing process on family members. Family communication during the testing process has received attention among high-risk families (20, 21). Issues of informing families of the mutation status of the index patient and subsequent actions of family members regarding their own risk are new areas of current study (22).

A few target groups have been studied, with more proposed. The most common target of study is the high-risk patient and/or family member, specifically the first-degree relative. Some research has explored ethnic or cultural differences in these samples, finding distinctive patterns in beliefs and approaches across cultures (23–25). Providers that act as gatekeepers to risk assessment have been subjects in studies, with findings suggesting that providers are underinformed about genetic testing (26–28). Finally, some studies have included persons at multiple levels of risk and are more generalizable, but few interventions have targeted this public health sample (29, 30).

Strengths of the Research Area. The strengths of this field include a multidisciplinary approach to the research questions, a focused line of research directed at high-risk patients and their families, the use of data from other areas as it applies to the study of issues in genetics, and consideration of a broad range of ethical, social, and legal issues in the current studies. Furthermore, multiple methodologies have been used to study the process of genetic risk information and testing, including qualitative methods, quantitative survey research, and randomized and nonrandomized intervention designs.

Weaknesses of the Research Area. This field is relatively new, and therefore, there is not a critical mass of studies to be reviewed. There is often less use of existing theoretical approaches to guide the study of the psychosocial correlates and consequences of genetic risk assessment and testing. Noteworthy exceptions include the Cognitive-Social Health Information Processing model (15, 31, 32) and self-regulation theory (33, 34). Additional development and consolidation of the available theoretical base is an area of clear research need.

Measurement approaches have grown with the field, but there are key gaps in the published literature on this topic. First, target study outcomes are difficult to define given the current scientific knowledge base. For example, it is unclear whether actually undergoing testing should be the desired outcome or whether satisfaction with one's testing decision is the more appropriate (and ethical) target outcome. Recently, articles have begun to address the difficulties in identifying outcome variables and have presented alternate strategies (*e.g.*, the use of process research) to assess counseling effectiveness (35–37). Related to this concern is the fact that most studies rely on short-term outcomes and fail to take a systematic longitudinal or developmental perspective on genetic risk decisions, correlates, and consequences (38).

An additional measurement issue relates to the potentially unique role of genetic risk as a risk factor, relative to other risk factors. It is unclear whether genetic risk is in some ways qualitatively different in its impact from other risk factors and, if so, why. An additional question that arises is whether genetic-specific measures of variables such as satisfaction, quality of care, and negative affect are more appropriate than general measures that have been developed for a broad range of health situations. Measurement of risk perceptions, one of the key short-term outcomes in this field, is fraught with measurement problems and is in need of research attention (32).

Finally, a key design weakness in this area is the reliance on self-selected sampling from high-risk clinics and from volunteer samples. Self-selected samples may be more resilient to adverse outcomes, and this may account for the lack of adverse psychological reactions noted in the literature (39). Alternatively, these reactions may well exist but are rare, even in samples that are generalizable to the geographical area of recruitment. A population-based sample can be defined as a sample that has known properties and that can be compared with the population from which it is recruited. The consistent differences observed in health and psychological functioning between volunteer and population-based samples in other research areas highlights the need to broaden our sampling methods and to pay attention to the impact of different referral and recruitment methods in the outcomes under study. The use of population-based sampling, which is the collection of data from a population with defined characteristics, will increase our ability to interpret and generalize study results.

Directions for Future Research. Four main areas of research priorities were identified. Some of these priorities can be addressed through "quick fix" remedies and accomplished in the context of existing studies. However, most of these priorities require more innovative scientific approaches, including conceptual and methodological development.

First, more integrative and comprehensive models of risk communication and risk information provision are needed, beyond the traditional genetic counseling approach. Greater attention needs to be given to theory-based and hypothesis-driven

research and to more precise identification and measurement of target outcomes.

Second, research addressing the long-term consequences of counseling, testing, and choices after testing is needed. These studies should include follow-up of existing cohorts and registry samples to identify any long-term adverse effects or difficulties with current models, as well as the testing of innovative and more conceptually based models of information and support provision, including the application of new media approaches. Identification of the appropriate outcome variables and the potential mediator and moderator variables also needs to be a part of this agenda. Related to this, greater attention needs to be given to the familial and developmental context in which genetic assessment and testing decisions unfold.

Third, research in this field has to use care when recruiting participants and not draw conclusions based solely on volunteer samples from high-risk families. Cultural and ethnic differences have been identified in the few studies that have focused on diverse target groups (*e.g.*, Refs. 22, 24). A range of socioeconomic barriers and issues is just now being identified, and the meaning and import of those differences needs to be explored. In the past 5 years, we have obtained an emerging outcome database on high-risk, volunteer individuals. However, we are still not in a position to generalize these findings to a defined population because of the focus on potentially biased, self-selected samples. Encouragingly, the sampling issues that exist are ultimately easily addressable through more carefully designed research protocols. The research infrastructures funded by the National Cancer Institute to recruit population-based samples of high- and average-risk patients and family members could provide a fresh source of ideas, collaborators, and research participants in this area. For example, the Cancer Genetics Network (CGN) is a national network of centers specializing in the study of inherited predisposition to cancer. The CGN consists of eight centers and an Informatics Technology Group, which provides the supporting informatics and logistics infrastructure. The CGN enrolls individuals who have a personal or family history of cancer and who may be interested in participating in studies about inherited susceptibility to cancer. Enrollees provide information about their health and family history of cancer, in addition to information about sociodemographic factors. The CGN supports collaborative investigations on the genetic basis of cancer susceptibility, as well as mechanisms to integrate this new knowledge into medical practice. The CGN also addresses the associated psychosocial, ethical, legal, and public health issues by providing the enrollment data to qualified investigators or by providing study subjects from its registry information about more specialized research by approved investigators.

Finally, on the structural and political level, more must be done to consider other models of delivering genetic testing information besides the for-profit company-driven model. The modus operandi of the few biotechnology companies currently involved in producing and marketing genetic tests to healthcare providers and to consumers must be shaped by data and policy on what is appropriate, health promoting, and adaptive for the target groups. To accomplish this task requires that we consider alternatives to existing policy and practice in the monitoring of genetic testing.

Behavioral Oncology Roundtable 2: Biological Mechanisms of Psychosocial Effects on Cancer

Introduction. There is increasing interest among the scientific community and the lay public in how mind-body interactions influence disease processes. This interest has been driven partly by empirical evidence suggesting that psychological factors are associated with cancer outcomes and by claims that psychosocial interventions can increase survival. Over the past 20 years, a growing body of research has attempted to identify the biological mechanisms of psychosocial effects on cancer and to delineate the potential pathways through which psychosocial factors might influence cancer outcomes. Specific targets of study vary depending upon the nature of the research question and include healthy people at average or increased risk for cancer and cancer patients.

Key Findings and Goals of the Research Area. Whether psychosocial factors (such as psychological stress and adjustment, social support, and depression) are associated with cancer onset or progression remains an area of scientific inquiry and controversy (*e.g.* Refs. 40, 41). The biological mechanisms by which psychosocial factors might influence tumor development, growth, and metastases are currently under investigation. To date, the majority of studies of psychosocial effects on cancer, many of which were based on Burnet's immune surveillance theory (42), have focused on psychoimmunological pathways. In general, studies have reported an inverse relationship between stress and various indices of *in vitro* immune activity [*e.g.*, natural killer cell functional activity, lymphocyte proliferative response to mitogens, numbers and percentages of specific immune cell subsets (*e.g.*, Ref. 43)]. However, this relationship has not been consistently found across all studies. In other work (*e.g.*, Refs. 44–46), social support has generally been shown to be positively associated with greater natural killer cell functional activity, and depression has been consistently associated with immune dysregulation, primarily reflected by lower numbers of natural killer and helper T cells (47, 48) and higher levels of interleukin 6 (49).

In addition to observational studies, randomized clinical trials that explore the impact of psychosocial interventions (*e.g.*, cognitive-behavioral stress management, or group psychotherapy) have been used to test psychoimmunological pathways in cancer patients. Overall, the efficacy of psychosocial interventions in producing immunological change has been mixed, with some studies reporting results demonstrating enhanced immune activity (*e.g.*, Refs. 50–53) and other studies showing no effect (*e.g.*, Refs. 54–56).

On the basis of the existing data, there are three main goals for research. First, there is a need to identify and assess biological markers that have prognostic value and are associated with cancer risk, progression, or other clinically relevant outcome (*e.g.*, increased morbidity). For example, an increasing awareness of the role of cytokines in infectious processes and cancer-related morbidity calls for the measurement of biological markers beyond the repertoire of immune outcomes that have been historically used (*e.g.*, natural killer cell activity). In addition, recent studies (*e.g.*, Refs. 56–58) illustrate the importance of considering neuroendocrine mechanisms in cancer risk and progression. To date, biobehavioral research has had a limited impact in the cancer context, primarily due to a failure to demonstrate that the biological pathways or mechanisms assessed are of clinical relevance. Thus, behavioral researchers need to be aware of and familiarize themselves with the latest advances in relevant related fields, including immunology, genetics, molecular biology, and endocrinology, to incorporate appropriate biological markers into their research.

A second goal is to expand the research domain to include patient outcomes other than survival. Historically, studies have attempted to delineate the pathways between psychosocial fac-

tors and a given biological marker, with the ultimate goal of predicting survival as an end point. However, because survival is influenced by a multitude of factors, building a research agenda that is focused solely on this end point will inevitably predispose many studies to failure. Thus, cancer outcomes in addition to survival (*e.g.*, disease progression, patient response to treatment, cancer-related morbidity, and recurrence) should also be considered as viable endpoints in this research area.

A third goal is to understand the biobehavioral bases of risk behaviors that lead to cancer. For example, research has identified individual differences in genetic predisposition to cigarette smoking (*e.g.*, Refs. 59, 60), substance abuse, and risk-taking behaviors (*e.g.*, Ref. 56). Particular genetic polymorphisms have been linked to certain personality traits (*e.g.*, poor impulse control and novelty seeking) that are associated with a predisposition toward these behaviors (*e.g.*, Ref. 58). In addition, affective disorders (such as depression) are often associated with tobacco and alcohol use (*e.g.*, Ref. 59). A greater comprehension of the biobehavioral bases of risk behaviors would contribute to our ability to successfully modify or treat these risk factors through behavioral intervention and/or pharmacotherapy.

Strengths of the Research Area. There are a number of strengths that define this research area. First, this multidisciplinary field draws upon diverse areas of cancer research to inform its hypotheses and research questions. Second, when properly designed and conducted, this research can identify key biological mechanisms of action underlying psychosocial effects, which can then be rigorously tested in randomized intervention studies. Finally, appropriate treatment or modification of psychosocial or behavioral risk factors may yield significant positive effects on patient clinical outcomes such as cancer-related fatigue and treatment response.

Weaknesses of the Research Area. This field of study has been limited by conceptual weaknesses. In some cases, intervention studies have been carried out prematurely, without being guided by theory-based hypotheses, thereby hampering an understanding of the potential processes involved.

The impact of study findings has also been undermined by methodological weaknesses. The most common study design flaw is the failure to include an appropriate or relevant control group. To date, many observational studies and several intervention studies have used a repeated measures design in which psychosocial and immunological factors are assessed across various time points and the patient serves as his or her own control. The findings from these studies have contributed immensely to our understanding of potential biobehavioral pathways. However, the gold standard in determining causality and the directional nature of these pathways is the utilization of a randomized experimental design that compares the treatment condition to an appropriate control group. Although this has been difficult to achieve for many studies, thereby limiting the potential impact of research findings in the field, current studies are meeting this standard.

In addition, the selection and measurement of biological markers is often determined by what can easily be measured (*e.g.*, markers in peripheral blood or saliva) and when it can be measured (*e.g.*, during a clinic visit), rather than assessing the most relevant measures at optimal time points for understanding the mechanisms involved. Too often, logistical constraints in obtaining biological measures and methodological limitations such as small sample size lessen the resulting data's potential contribution to the field. Furthermore, replication of key findings is not commonly observed, although it is important to note that a failure to replicate is not specific to this particular field.

Finally, a salient weakness that needs to be addressed is the selection of appropriate patient samples. Psychoimmunological effects may be more relevant to and more likely to be observed among people with highly immunogenic tumors (*e.g.*, basal cell carcinoma, renal cell carcinoma, and cervical cancer). In these individuals, where the psychosocial-immune-tumor response link is definable, psychosocial intervention is more likely to yield discernable effects. Furthermore, stage of disease is an important factor to consider when testing psychosocial interventions, which tend to produce small to moderate immune effects. Interventions directed at individuals with late-stage tumors are less likely to demonstrate any significant biological changes as a result of the overwhelming effects associated with tumor biology.

Directions for Future Research. The accumulating data suggest that additional exploration of the role of psychosocial factors on cancer outcomes (*i.e.*, disease- and treatment-related morbidity, tumor progression, and survival) is warranted. A growing awareness of the complexity of biological measures and the bi-directional influence of the central nervous system and immune system illustrates the need for multidisciplinary perspectives. The field needs to continue to focus on promising areas of research by defining immunogenic cancer sites for studies relating to cancer progression, regression, and survival, as well as to expand the current research domain to include other cancer outcomes such as disease- and treatment-related morbidity (*e.g.*, fatigue and infection). Finally, there is a clear need to explore health disparities within this area of research and to extend research beyond the focus on more selected samples to include more population-based studies.

Three main research directions would significantly contribute to the existing knowledge and database in this field. First, there is a conceptual need to identify appropriate biomarkers and to extend biological assessments beyond the immunological to include genetic, neuroendocrine, and physiological measures. Assessments of functional activity such as DNA repair mechanisms and apoptosis may also provide insight into the various pathways underlying psychosocial effects on cancer outcomes. Incorporation of these types of assessments would require that investigators have multidisciplinary training and/or a multidisciplinary team of collaborators. In addition, research teams should develop a closer interface with clinicians to gain a greater understanding of the clinical relevance of these types of biomarkers.

Second, there is a need to strengthen study design and methodology. Findings are often limited by the use of nonexperimental research designs or by sample size constraints. Moreover, choosing the appropriate group is crucial. A greater focus on at-risk individuals (*e.g.*, intraepithelial neoplasia or precancers) may translate into clinical benefits in terms of prevention and regression of precancerous lesions (*e.g.*, Ref. 60). Biobehavioral studies that are conducted within the context of a chemoprevention trial may provide the most pertinent and timely information.

Third, additional research on health disparities is needed to shed light on the potential biobehavioral mechanisms that may account for differential incidence and mortality rates across groups. Findings from other research domains (*e.g.*, cardiovascular disease) have demonstrated ethnic and racial differences in stress reactivity that, by extension, may also contribute to discrepancies in cancer outcomes. Some prior studies may not have adequately controlled for socioeconomic differences

across racial or ethnic groups. Therefore, it has been difficult to determine whether observed differences are because of biological or socioenvironmental factors. Nevertheless, differences in physiological responses to stress, whether because of biological mechanisms, socioeconomic factors, or some combination of the two, can result in differential uptake of health behaviors (*e.g.*, tobacco use, diet, or exercise), with subsequent effects on cancer risk, treatment response, and cancer-related morbidity and mortality.

Behavioral Oncology Roundtable 3: The Role of Risk Perceptions in Cancer Screening Adherence

Introduction. Cancer risk perceptions represent a core construct in cancer prevention and control research. Perceptions of one's own risk for cancer appear in most behavioral models are researched in multiple patient and nonpatient settings, and risk estimates are given by providers as potential motivators for behavior change.

Goals of the Research Area and Key Findings. Studies that explore the role of risk perceptions in health behavior have involved selected groups such as high-risk individuals (*e.g.*, participants in a genetic testing program; Refs. 30, 61, 62) and have focused on detection behaviors (*e.g.*, prostate and colon cancer screening; Refs. 63, 64). The majority of these studies have found that the individual's perception of cancer risk is only a moderate predictor of screening behavior (65), which often disappears in final measurement models (*e.g.*, Refs. 66, 67). The emerging data suggest that cancer risk perceptions need to be considered as one component of a greater constellation of inter-related disease-specific cognitions and affects (32, 68–70).

Strengths of the Research Area. Cancer-related perceptions of risk are multifaceted constructs that may be interpreted in several ways for any one individual. For example, perceived risk for cancer may be associated with the risk of developing disease, the risk of side effects associated with treatment of the disease, or the risk of disease recurrence. Accumulating evidence over the past years supports the multifaceted nature of the risk perception construct (*e.g.*, Refs. 71–74). Such an interpretation is additionally supported by recent cognitive-affective theoretical perspectives (*e.g.*, Refs. 68, 75), which stipulate that a complex pattern of cancer-relevant beliefs and expectations (*i.e.*, disease representations) influence a person's overall risk perception.

To date, the strengths of this research area can be seen not so much in the answers that it has yielded across studies, but in the questions that have been raised. The heterogeneous results obtained with the risk perception construct underscores the need to examine issues such as how individuals process and understand risk-related information, how they react effectively to risk feedback, and how best to communicate risk information. The findings additionally emphasize the need to imbed the perceived risk construct in current theories of health and behavior. In particular, the study of risk perceptions needs to go beyond the reliance on the perceived risk variable as the single predictor of behavior or adjustment in different adherence contexts (32).

Weaknesses of the Research Area. There are a number of possible explanations for the weak effects of the risk perception construct. First, limitations in the way in which risk is currently measured may act to minimize or mask the actual effects of this variable. In general, there is little variation in the measurement of risk, with two main commonly used approaches: (*a*) as an estimate of the percentage likelihood of developing the cancer type, ranging from 0 to 100% (*e.g.*, Refs. 63, 76); and (*b*) as a Likert-type scale, with descriptions of the likelihood of developing the disease ranging from very low to very high (*e.g.*, Refs. 64, 77, 78).

Individuals may have difficulty interpreting these questions because of differing basic conceptualizations or grounding points, from which they estimate risk (79). Researchers usually do not assess how participants interpret closed-ended questions such as the ones just described. However, such assessments are warranted because individuals differ predictably in their personal experiences, beliefs, expectations, and somatic experiences related to cancer, which in turn affect personal risk assessments (68, 75).

It could be the case that inaccurate personal risk perceptions (too high or too low) are related to lack of information about disease incidence rates. However, research has repeatedly demonstrated that individuals often persist in their inaccurate risk beliefs, even after extensive counseling (80). The cognitive-affective, self-regulatory framework offers an explanation for these findings: because risk perceptions result from stable individual belief systems, are grounded in personal experiences, and are connected to somatic events, they become deeply embedded in a person's representation of the self (32). Consequently, the addition of new information that does not address long-held beliefs, expectations, and somatic experiences or that contradicts these existing belief structures will not be potent modifiers of the individual's risk perceptions.

Directions for Future Research. A growing awareness of the limitations of current approaches to the assessment of cancer risk perceptions and the acknowledgment of the complexity of the risk construct literature illustrate the need for a multidisciplinary perspective in this area. Researchers must begin to adopt a conceptually grounded multidisciplinary approach, to integrate advances in theory model building from diverse subareas of social and cognitive science, and to embrace novel methodologies for assessing this construct.

On the basis of the existing data, four main directions for additional research can be identified. These directions include the expansion of the overall scope and depth of cancer risk investigations, with a specific focus on groups that have been otherwise neglected. Most importantly, we need to expand the conceptual domain to include a wider perspective on subjective interpretations and definitions of risk. There is a need to move beyond the current unidimensional measurement paradigm to supplement existing methods of risk assessment with multidimensional methods used in areas such as social psychology, cognitive psychology, and marketing. For example, risk perceptions may be influenced by heuristics and biases as described by Kahneman (81), by information processing tendencies (68), and by different mood states (82).

A second direction is to develop more sophisticated measurement tools for assessing risk perceptions. Applying a broader theoretical and empirical base from diverse disciplines will help to not only fine-tune existing survey-type measures of risk assessment but also to use more diverse approaches to risk assessment through the use of qualitative methodologies. Qualitative methods would greatly elucidate what we know about how individuals think and how they react emotionally when responding to perceived risk questions. Information from these studies could then be used to develop more rigorous quantitative assessment tools.

Third, to date, few studies assessing risk have used an experimental design; thus, the causative role of risk perceptions in relation to cancer screening behaviors has not been ade-

quately delineated. In addition to fully develop a broad-ranging understanding of risk perceptions, cancer researchers need to extend their research perspectives to include what is already known about risk-related adherence behaviors from other disease contexts such as HIV/AIDS (*e.g.*, Refs. 83, 84) and cardiovascular disease (*e.g.*, Refs. 85, 86).

Finally, there is a need to identify the role of background factors (such as gender, ethnicity, age, culture, disease site, and socioeconomic status) as they relate to risk perceptions. As such, the analysis of risk needs to encompass the broader social/disease context because it is not clear to what extent risk perceptions are stable across different situations, disease models, and population-based settings. For example, research to date has focused primarily on risk perceptions for a specific cancer type (87–90). A thorough understanding of cancer risk will require an exploration of how individuals encode their vulnerability across a number of different cancer sites. Similarly, the specific stage within the cancer continuum may differentially influence an individual's risk perceptions. For example, perceptions of cancer risk for an individual contemplating participation in a chemoprevention trial may be quantitatively and qualitatively different from the perceived risks associated with participation in a cancer treatment trial.

Behavioral Oncology Roundtable 4: The Contribution of Tailored and Targeted Interventions to Cancer Prevention and Control Research

Introduction. Research increasingly points to the importance of health behaviors in the primary prevention and early detection of cancer and other chronic diseases. A growing body of research has demonstrated that tailored and targeted interventions are generally more effective than one size fits all behavior change programs. Many unanswered questions remain, however, such as the relative effectiveness of tailored communications compared with other state-of-the-art intervention approaches, the circumstances under which tailoring *versus* targeting should be used, and the mediators of the effectiveness of tailored communications.

In terms of definitions for this article, the term targeting (based on social marketing principles) refers to audience segmentation and analysis using formative research that leads to interventions designed to appeal to group-level characteristics such as demographics or other shared characteristics (*e.g.*, cultural beliefs). The term tailoring, on the other hand, is used to describe interventions that vary according to individual-level characteristics. Tailored communications are assessment based and should include personalized information that is relevant to the identified psychosocial constructs, as well as providing behavioral feedback (90).

Key Findings and Goals of the Research Area. Several recent review articles have summarized the evidence for the effectiveness of computer-tailored communications (92–94). Skinner *et al.* (92) reviewed the first 12 published studies, which spanned a variety of health behaviors, including diet, physical activity, smoking, and mammography screening. Findings showed that tailored print materials outperformed nontailored information in terms of process (*e.g.*, attention, recall, readership, or perceived relevance) and outcome (*e.g.*, fat intake or obtaining a mammogram) measures. Furthermore, a review of tailored smoking cessation interventions showed generally favorable outcomes of tailoring, especially among precontemplators and when combined with nicotine replacement therapy (95).

The evidence has been less clear when tailored materials have been compared with other intervention modalities such as telephone counseling. Additional discussion of mixed findings can be found in the review of Rimer and Glassman (94) and in a recent experimental study with nicotine replacement and computer-tailored materials (96). Additional limitations noted in the articles included relatively short follow-up periods and lack of standardization of many elements of tailoring methods, including differing theoretical frameworks, number and choice of tailoring variables, decision rules and algorithms, and process and outcome measures.

Currently, tailoring research includes a continued focus on the effectiveness of print communications, as well as the use of new media such as the Internet, CD-ROM, and automated telephone systems (97–99). Although the bulk of the evidence supports the efficacy of tailoring, some studies have shown no added effects of tailored messages over well-designed nontailored information (100, 101). Studies have begun to investigate mediating steps in the process between exposure to tailored information and behavior change such as the role of cognitive processing of messages, effects of tailoring to specific psychological characteristics, and the relative impact of varying message sources and characteristics (102–105). In addition, Kreuter (91) have suggested that targeted materials can perform as well as tailored information when there is a good match between participant characteristics and group-level targeting variables (*e.g.*, when there is a relatively high degree of homogeneity in behavioral determinants in the group under study).

Strengths of the Research Area. Several strengths of the research on tailored interventions can be been identified. First, based on well-designed randomized trials, there is a growing body of evidence demonstrating that tailored interventions can achieve health behavior changes, including diet, physical activity, smoking, and screening behaviors such as mammography (106). Second, there is evidence to suggest possible mechanisms whereby tailoring may exert its effects based on theories of information processing, social psychology, and persuasion (32, 102–104, 106, 107). Third, more recent research indicates that tailored interventions are effective for minority and lower income groups, thereby offering a potential avenue to reduce health disparities (98, 108). Finally, with the growing use of and access to innovative technologies such as the Internet, new opportunities are emerging for broad dissemination and testing of tailored health behavior change interventions.

Weaknesses of the Research Area. Studies that have directly compared the efficacy of tailored interventions to other strategies such as telephone counseling have produced inconsistent results (92). It is important to note, however, that traditional interventions such as in-person and telephone counseling, by definition, constitute tailored modalities of information provision. In contrast to programmed tailored messages, however, the counselor is able to provide on-the-spot, spontaneous individualization of information to the participant's personal and situational characteristics. One might expect, therefore, an equivalent or superior outcome from highly trained, skilled counselors who can deliver the message in a dynamic interactive fashion that takes advantage of social and nonverbal cues, rather than drawing from predetermined message libraries and algorithms to provide the feedback. In addition, computer-tailored interventions rely on assessment of psychosocial and behavioral construct measures to determine tailored feedback. However, may of these measures have never been subjected to psychometric testing or validation in diverse groups and cultures.

Follow-up periods generally have been short (several

months), and many studies have relied on self-report information to assess outcomes. More evaluative research is also needed regarding the relative impact of tailoring using new technologies such as the Internet. In addition, most tailored communications generally have focused on individual-level behavior change, whereas many health behaviors are strongly influenced by other levels of change in the socioecological model such as social and community norms and environmental factors (109). Greater attention needs to be paid to multilevel interventions that incorporate tailoring as one of a number of coordinated and integrated interventions (108). There is also a need to more systematically extend tailoring studies beyond screening and behavioral change outcomes to provide a greater focus on decision-making and long-term adjustment.

Directions for Future Research. Tailored and targeted cancer communications have shown promise for cancer prevention and control research. Future studies should be designed so that theories, measures, and mechanisms can be elucidated and so that efficacious interventions can be compared and replicated. There are three broad directions for future research. First, there is a need to specify and study the relative efficacy of differing amounts of tailoring and targeting in intervention studies. Because many interventions include both individualized tailoring and group-level targeting, researchers should specify which parts of the interventions are tailored *versus* targeted and the rationale for those choices.

Second, research is needed to understand the "black box" of unanswered questions that could explain whether and why tailored interventions are effective. To advance the field, it is vitally important to foster the next generation of studies that can add to our understanding of the factors that explain or mediate the processes and outcomes of tailored interventions, including greater specification of presumed underlying mechanisms, theories, and contextual factors.

The key research questions under this goal include the following.

1) What variations between groups or individuals are most predictive of who will—or will not—benefit from tailored and/or targeted communications (110)? Some research suggests that variation is greater within than between cultures, arguing for tailoring as well as targeting. Different cultural groups and individuals within those groups may vary on many issues such as trust, access to information and media/technology, literacy, language, beliefs, and cultural and ethnic identity; however, it is not clear whether tailoring to some or all of these variations will increase efficacy (111).

2) What are the contextual factors that may explain under what circumstances or situations tailoring may be most effective? This may include recognizing the influence of factors such as teachable moments; for example, diagnosis of an illness such as cancer in oneself or a family member may heighten motivation for health behavior change (112, 113). Affective states such as depression or anxiety as well as situational, environmental, and developmental factors all may play a powerful role in determining a person's ability to comprehend, process, and act on health information.

3) What are the basic mechanistic factors underlying tailored communications? Understanding of mechanisms will require laboratory studies of communication and information processing, qualitative studies to observe the processes by which people receive, process, use, and incorporate tailored information into their behavior change efforts, and dose and timing studies to determine the amount of intervention necessary to produce change. In addition, in studies where multiple behaviors are included in interventions (*e.g.*, diet and physical activity), research should address how individuals choose and prioritize among these behaviors and how best to design and evaluate communications to facilitate these decisions (114).

4) What media are most effective and cost-effective? Studies are needed to evaluate the appropriateness, understandability, and usability of different media used for tailoring, including the Internet and interactive technologies such as handheld computers and automated voice recognition, as well as more traditional media such as print and telephone counseling (115).

5) What theories and models should underlie tailored and targeted communications? Most research studies of tailoring to date have been based on a relatively small number of health behavior theories based in cognitive psychology, including the transtheoretical model or stages-of-change model, Health Belief Model, and Social Cognitive Theory (116–118). We know relatively little regarding the relative mediating effects of these variables and constructs in tailored interventions or how many variables is the optimal number for tailoring (32).

General Conclusions. There is remarkable consensus regarding future directions in the four areas of research. The areas of priority revolve around three key issues: (*a*) incorporation of more comprehensive and integrative conceptual models; (*b*) greater sophistication and advances in methodological approaches; and (*c*) identification of the individual and group characteristics of the target population. First, all four areas call for the further development of more integrative and overarching conceptual models to systematically assess and address the phenomena under study. Greater theoretical consistency and richness would be invaluable for accomplishing a number of goals, including the use of more comprehensive, unifying, and predictive models; the formulation of more hypothesis-driven research questions; the resolution of methodological confusions; as well as the design and evaluation of more refined measurement approaches and more effective intervention strategies.

Second, there is a uniform need for the application of sound methodological research principles. In particular, all four areas would benefit from more precise measurement of the key constructs under consideration, as well as greater rigor in study design, including long-term evaluation. Measurement improvements are particularly important for the areas of Behavioral Approaches to Cancer Genetic Assessment and Testing (Roundtable 1) and the Role of Risk Perceptions in Cancer Screening Adherence (Roundtable 3). Advances in study design and selection of appropriate control groups are critical for the areas of Biological Mechanisms of Psychosocial Effects of Cancer (Roundtable 2) and the Contributions of Tailored and Targeted Interventions to Cancer Prevention and Control Research (Roundtable 4).

Finally, a key agenda for future research is to delineate the characteristics of target populations that need to be considered. This agenda requires greater attention to the sample selection procedures in terms of such factors as the inclusion of disadvantaged individuals into research projects, the use of population-based recruitment, and more precise characterization of the target samples as predictors and influences on outcomes.

The outcomes of the roundtables show the breadth, as well as the depth of behavioral contributions to cancer prevention and control. Furthermore, they point to the importance of linking psychosocial investigations to the broader behavioral science base that guides them and of achieving more seamless collaboration between behavioral science investigators and their public health and medical science collaborators.

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Facilitating Informed Decision Making About Breast Cancer Risk and Genetic Counseling Among Women Calling the NCI's Cancer Information Service

SUZANNE M. MILLER,[1] LINDA FLEISHER,[1] PAGONA ROUSSI,[2] JOANNE S. BUZAGLO,[1] ROBERT SCHNOLL,[1] ELYSE SLATER,[1] SUSAN RAYSOR,[1] AND MELANIA POPA-MABE[1]

[1]Fox Chase Cancer Center, Fox Chase, Pennsylvania, USA; [2]Aristotle University of Thessaloniki, Thessaloniki, Greece

Despite increased interest among the public in breast cancer genetic risk and genetic testing, there are limited services to help women make informed decisions about genetic testing. This study, conducted with female callers (N = 279) to the National Cancer Institute's (NCI's) Atlantic Region Cancer Information Service (CIS), developed and evaluated a theory-based, educational intervention designed to increase callers' understanding of the following: (a) the kinds of information required to determine inherited risk; (b) their own personal family history of cancer; and (c) the benefits and limitations of genetic testing. Callers requesting information about breast/ovarian cancer risk, risk assessment services, and genetic testing were randomized to either: (1) standard care or (2) an educational intervention. Results show that the educational intervention reduced intention to obtain genetic testing among women at average risk and increased intention among high-risk women at 6 months. In addition, high monitors, who typically attend to and seek information, demonstrated greater increases in knowledge and perceived risk over the 6-month interval than low monitors, who typically are distracted from information. These findings suggest that theoretically designed interventions can be effective in helping women understand their cancer risk and appropriate risk assessment options and can be implemented successfully within a service program like the CIS.

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Address correspondence to Suzanne Miller, PhD, Director of Psychosocial and Behavioral Medicine Department, Fox Chase Cancer Center, Fox Chase, PA, USA. E-mail: SM_Miller@fccc.edu

Publication of the first draft of the sequence of the human genome was published in 2001, forging new territory and creating numerous implications for ethics, science, education, and medical practice (Collins & Guttmacher, 2001). This new era of medical research has identified specific genes that predispose individuals and families to certain cancers, which have the potential of leading to new approaches to treating and even preventing disease. A prime example is the media and public focus around the identification of the *BRCA1* (Miki et al., 1994) and *BRCA2* genes (Mullan et al., 2001; Pavelic & Gall-Troselj, 2001; Wooster et al., 1995), which have been shown to increase an individual's risk for breast and ovarian cancer. This public focus has led to a growing interest in obtaining information, education, and counseling about breast genetic risk and genetic testing, as well as one's potential options for surveillance and prevention. Unfortunately, there are a limited number of trained providers and services to educate women about the complex determinants of inherited risk or the process and content of risk assessment/genetic testing. This has created a gulf between public interest and informed sources of evidence-based information and services.

A key issue is how best to facilitate the appropriate use of genetic testing, especially among women who are not at increased familial risk. Rather, it is important to direct women to more appropriate disease management approaches. Studies have shown that 40% (Gwyn, Vernon, & Conoley, 2003) to 93% (Andrykowski, Boerner, Salsman, & Pavlik, 2004) of women in the primary care setting report that they would be interested in genetic testing or have intentions to pursue genetic testing. Thus, despite the growing medical and public awareness and interest in genetic testing for cancer susceptibility, women may not have the information they need about the relevance of genetic testing for them personally. In particular, there is a tendency for women to overestimate their risk for inherited breast cancer and to misunderstand the limitations of available test options (Iglehart et al., 1998). On the other side of the issue, approximately 80% of respondents with family histories of breast or ovarian cancer are highly interested in undergoing testing (Berth, Balck, & Dinkel, 2002; Struewing, Lerman, Kase, Giambarresi, & Tucker, 1995). However, only about 50% of these individuals, ultimately opt to be tested (Biesecker et al., 2000; Botkin et al., 2003). Among the reasons why women who are candidates for genetic testing decline participation include the uncertainty of the test result, psychological distress, concerns of family stress, health insurance related issues, and limited management options (Hadley et al., 2003; Lerman et al., 1999; Lerman, Narod et al., 1996; Lerman & Shields, 2004). Thus, for both average- and high-risk women, there continues to be a gap between women's perceptions about their own risk and the appropriate uptake of genetic services. This study was designed to develop and evaluate an enhanced intervention in an established science-based information service (NCI's CIS) to assist women in understanding the hallmarks of inherited disease and the complexities of genetic testing (Miller et al., 2004).

Genetic counseling services through academic and research institutions have increased over the past few years. Currently, 386 genetic counseling programs are identified in NCI's PDQ on cancer.gov. However, there are few other providers who have the training and expertise to offer the in-depth education and support to assist women in understanding their risk (Cornfeld, Miller, Ross, & Schneider, 2001; Green et al., 2004; Lerman & Shields, 2004; Mouchawar, Klein, & Mullineaux, 2001; Rich et al., 2004). While some medical specialties appear to be more familiar with genetics (e.g., pediatrics, obstetrics and gynecology, and oncology), other primary care providers (e.g., family practitioners and general internists) have less

exposure to genetics, making mainstreaming genetic counseling and education more of a challenge (Collins & Guttmacher, 2001). Given increased interest among women about genetic testing, new educational approaches and channels are warranted to address the lack of services.

The Cognitive-Social Health Information Processing (C-SHIP) model (Miller et al., 1996) is a theoretical framework that integrates both cognitive and affective components that can help to guide the design and evaluation of educational and risk assessment interventions. The C-SHIP model draws on the common elements of health behavior theories to facilitate risk-related information processing, decision making, adaptation and execution of health behaviors (Bandura, 1989; Bandura, Adams & Beyer, 1977; Carver & Scheier, 1981; Curry & Emmons, 1994; Janz & Becker, 1984; Leventhal & Shearer, 1989). The underlying premise of the C-SHIP model is that individuals respond more adaptively, in terms of their decision making, when they are provided with information in a systematic way that helps them to more thoroughly process and prepare for their cognitive and emotional response to risk-related feedback. This approach entails addressing the individual's encoding (e.g., perceived cancer risks), expectations and beliefs about possible outcomes, risk-related goals and values, and self-regulatory coping skills (Miller et al., 1996). By activating these cognitive-affective elements in an interactive, proactive, and comprehensive fashion, an individual can more thoroughly evaluate the pros and cons of genetic testing and thereby generate and maintain action plans that appropriately correspond to her own risk status.

Educational interventions need to address the range of affective and cognitive issues that are pertinent to understanding inherited risk and the process of high-risk counseling and genetic testing to facilitate informed decision making. By presenting feedback about the nature of breast risk, genetic testing, and the benefits and limitations of genetic testing, health communications can more effectively provide information that corresponds to individual needs and level of risk (Fischhoff, Bostrom, & Quadrel, 1997; Slovic, 1986). For average risk people, enhanced communications can allow them to accurately reconstrue their own risk levels, their expectations about genetic testing, and their own values and goals about what actions they should take.

An additional aspect of the C-SHIP model is that individual differences in how people attend to information have been found to play a role in how they respond to risk feedback. Specifically, we have focused on "monitoring," a key prototypic or "signature" information-processing style in response to health-related threats (Miller, 1995). High monitors generally scan for, and magnify, threatening health-related cues, whereas low monitors distract from, and downgrade, threatening information (Miller et al., 1996). These signature responses have been found to predict individual differences in cognitive-affective responses and coping behaviors to cancer risk-related stressors. High monitors exhibit a signature informational processing style in which they perceive themselves to be at greater risk for developing cancer than low monitors, independent of actual levels of risk (Fang, Miller, Daly, & Hurley, 2002; Schwartz, Lerman, Miller, Daly, & Masny, 1995). They also tend to feel more susceptible to cancer (Fang et al., 2002), to seek more knowledge about cancer (Ong et al., 1999; Rees & Bath, 2000; Steptoe & O'Sullivan, 1986), and to believe that genetic testing should be available even if the physician advises against it (Benkendorf et al., 1997). Because a person's expectancies, emotions, goals, and values can influence how risk information is processed and acted upon (Miller

et al., 1996), these individual differences may need to be taken into consideration when evaluating the impact of risk communications.

The NCI's CIS provides an ideal opportunity to implement and evaluate the impact of a theory-based educational intervention (Bright et al., 2005; Heimingder et al., 2005; Marcus et al., 2005; Fleisher et al., 1998; Marcus, 1998) to improve women's understanding of inherited risk for breast and ovarian cancer and the process and purpose of genetic testing and counseling of women at high risk of breast cancer, as well as to enhance women's readiness to pursue risk assessment if appropriate. It is important to evaluate within a "real-world" setting, strategies to address women's needs for more information in light of limited educational resources through primary care and public health programs. This study, conducted with 279 female callers to the NCI's Atlantic Region CIS, was designed to evaluate the hypothesis that among women at average risk, the intervention would increase knowledge and decrease risk perceptions and intentions to obtain genetic testing. Conversely, for high-risk women, the intervention would increase their intention to obtain genetic testing and increase risk perceptions. Finally, we hypothesized that high monitors, who tend to focus on threat-related cues, would report increased intentions to obtain genetic testing, greater risk-related knowledge, and greater risk perceptions compared with low monitors, who tend to distract from threat-related information.

Methods

The study was implemented within the NCI's CIS Atlantic Region office. The CIS has been providing the public with information about cancer research, prevention, risk factors, symptoms, diagnosis, and treatment since 1976 (Thomsen & Ter Maat, 1998). The CIS offers a variety of ways to reach professional information specialists, via the toll-free telephone number (1-800-4-CANCER), *LiveHelp* instant messaging service offered at NCI's website (www.cancer.gov), and e-mail inquires sent to NCI's website.

Participants

Women were eligible for the study if they were over age 18 and expressed concerns about their risks for breast or ovarian cancer or requested information about risk assessment services or genetic testing during a self-initiated call to the CIS. Those who consented were randomized to receive standard care or the educational intervention at the end of usual service.

Procedure

Eligible participants were recruited during their self-initiated telephone contact with the CIS (baseline). At the end of usual service, CIS information specialists obtained consent and conducted baseline interviews using the computer assisted telephone interview (CATI) system designed for the project. The data were stored in the CATI system that was shared by the CIS and the Psychosocial and Behavioral Medicine Program at Fox Chase Cancer Center (FCCC). Consenting participants were randomized by the CATI system to either the intervention or to the standard care group. The impact of the intervention was assessed by research staff through telephone interviews, at three time points: 2 weeks, 2 months, and 6 months postintervention. Actual risk was assessed using the Gail model (Gail et al., 1989) in the 2-week or

2 month follow-up assessment. Based on their Gail score, participants were divided into high- and average-risk groups for breast cancer primarily for analyses.

Intervention Development

The standard and enhanced intervention protocols were developed through a formative evaluation, including structured interviews and focus groups with women at actual or perceived high risk for inherited breast or ovarian cancer or both, with cancer genetic counseling professionals, and with women from the lay population. An extensive training program for CIS information specialists was developed and implemented to prepare them to respond to questions from callers.

The educational intervention was guided by the C-SHIP model (Miller & Diefenbach, 1998) and addressed key constructs including individual encoding of risk (with an additional component including taking a family history), knowledge-based self-regulatory processes (in-depth education regarding the hallmarks of inherited disease), beliefs, and expectancies (discussion of the pros and cons of genetic testing). In addition, they proactively provided them with information on the hallmarks of inherited breast cancer, assisted them in elucidating their own family history, discussed the benefits and limitations of genetic screening, referred individuals to a high-risk/genetic counseling program (if requested or appropriate), and informed them about the process involved in genetic counseling. Also, a detailed family history evaluation was completed and sent to the participants to assist them in exploring their understanding of inherited risk and their knowledge about their own family history. To complement the more detailed information provided in the "enhanced" intervention, an additional NCI publication was provided, which included an in-depth explanation of the issues surrounding genetic testing. The CIS information specialists who administered the enhanced interventions had received specialized training on basic genetics, cancer patterns and risk assessment, genetic counseling, genetic testing and informed consent, and health behaviors.

Standard care was a protocolized format of the CIS usual service created to standardize the provision of general information about cancer risk and referral to the NCI-approved high-risk counseling/genetic testing if appropriate. Women in the standard care group received all current CIS information on breast/ovarian cancer risk factors and general information about patterns of inherited risk. The information specialist addressed all questions that were raised during the call using NCI and other identified resources, referred women to their primary care provider for more assistance, and referred those with a family history to an NCI-approved high-risk program, when appropriate (Figure 1). The standard care group did not receive the proactive educational intervention focused on the hallmarks of inherited breast cancer, the pros and cons of genetic testing, or discussion about their own family cancer history.

Measures

Background Variables

Background variables, obtained at baseline, assessed sociodemographic variables (e.g., education, age, ethnicity), personal history of breast and ovarian cancer, as well as previous participation in a cancer risk assessment.

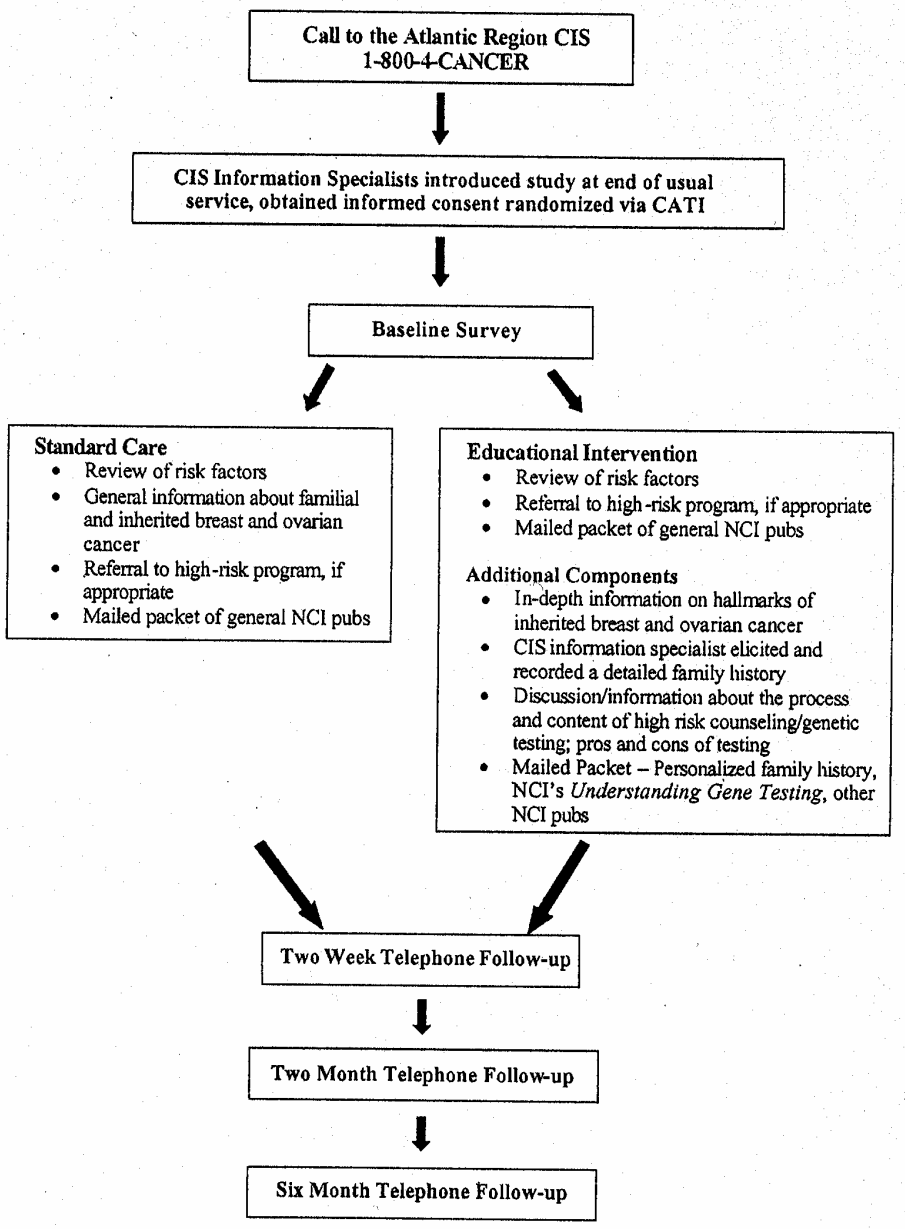

Figure 1. Study intervention and design.

Outcome Variables

Intention to Obtain Genetic Testing. Intention to pursue genetic testing was assessed at all four time points (e.g., baseline, 2-week, 2-month, and 6-month follow-up). Participants were asked to indicate which statement best described their situation: (1) had participated in a risk assessment and counseling program in the

past 6 months; (2) planning to contact a risk assessment and genetic counseling program in the next 30 days; (3) planning to contact a risk assessment and genetic counseling program in the next 6 months; (4) considering contacting a risk assessment and genetic counseling program but not really sure and have made no specific plan; or (5) not considering contacting a risk assessment and genetic counseling program.

Knowledge. Knowledge about breast and ovarian cancer was assessed at baseline and follow-up using two sets of questions. The first set focused on women's unprompted knowledge of known risk factors. The second set was composed of 17 true/false items, adapted for this study (Ondrusek, Warner, & Goel, 1999). Examples include the following:

- "Many women who do not have any of the known risk factors still get breast cancer."
- "There are no real disadvantages to pursuing risk assessment and genetic testing."
- "Testing for breast cancer gene mutations can tell a woman if she has breast cancer."

Two scores from the 17-item scale were calculated based on true/false responses, one for general cancer knowledge, consisting of four items, and one for knowledge specific to breast and ovarian cancer, consisting of nine items.

Perceived Risk. Perceived risk for breast and ovarian cancer was assessed at baseline, 2 weeks, 2 months, and 6 months postbaseline. Participants were asked to estimate their perceived risk for breast cancer by comparing their personal chances of getting breast cancer with women their same age, using a scale of 1 (i.e., very much lower than average) to 5 (i.e., much higher than average). This measure is used consistently in the literature to determine perceived risk.

Moderator Variables

Monitoring Attentional Style. Monitoring attentional style was assessed at the 2-week follow-up using the Monitoring-Blunting Style Scale (Miller, 1987) that measures coping responses to four structured stress-evoking scenarios (e.g., going to the dentist). For each of the four scenarios, participants are instructed to indicate which of eight potential responses would characterize their actions. Four of the responses to each scenario are indicative of a monitoring style and four are indicative of a blunting style. A total monitoring score (range 0–16) was computed for each participant by summing the number of monitoring strategies endorsed within each of the four scenarios. A median split was used to create high and a low monitoring groups. Reliability, discriminative validity, and utility of the MBSS are well established in the oncologic context (Miller, 1995).

Actual Risk. Actual risk was assessed based on the Gail model during the 2-week or 2-month follow-up. Based on this assessment, participants were categorized as high risk if their Gail score was over 1.6 and average risk if it was 1.6 or under (Gail et al., 1989).

Satisfaction With the CIS

Five items (5-point Likert scales) assessed user satisfaction with the CIS services at the 2-week follow-up, including their overall satisfaction, their satisfaction with the

mailed materials, their satisfaction with the initial call to the CIS, how likely they would be to call again, and to what extent they would recommend the service to others.

Results

Background Analyses

Accrual of Sample. As shown in Table 1, CIS information specialists offered the study to women who met study eligibility criteria ($N = 492$). Of these, 322 (65%) consented to participate, but out of these initial consenters, 43 (13%) dropped out during the initial stage of baseline data collection. The reasons cited for this initial drop-out were the additional time required by the study intervention (i.e., the study intervention started at the end of the standard CIS service) and lack of interest. Therefore, 279 (87%) women completed the baseline and educational intervention and were considered the study sample. These women were contacted at three points in time following baseline (2 weeks, 2 months, and 6 months). At 2-week follow-up, 203 (73%) of 279 participants were reached, consented again, and completed the telephone survey. At 2-month follow-up, attempts were made to contact all the baseline consenters ($N = 279$), including those who were not reached at 2-week postbaseline. Out of these, only 199 (71%) completed the telephone survey and consented again. At 6-month follow-up attempts, 175 completed the final telephone survey. Even though the study protocol allowed for up to 13 attempts to contact participants, some participants could not be reached. Those who were contacted and declined further participation in the study offered the following reasons for dropping out: personal health problems, no longer being interested in the study, believing that there was nothing to gain from participation, and not wanting to think about cancer risk. There was no differential attrition across study conditions. At baseline, however, women who dropped out had higher perceived risk for breast cancer ($t\ (151) = -2.00$, $p < .05$; women who dropped out: $M = 4.49$, $SD = 2.05$; women who remained: $M = 3.98$, $SD = 1.78$).

Table 1. Study accrual across baseline and follow-up interviews

	Baseline		2-week follow-up		2-month follow-up[1]		6-month follow-up[2]	
	N	%	*N*	%	*N*	%	*N*	%
Number eligible	492		279		279		199	
Number consented	322	(65)	–	–	–	–	–	–
Number dropped out	43	(13)						
Number not reached/declined	–	–	76	(27)	80	(29)	24	(12)
Number completed	279	(87)	203	(73)	199	(71)	175	(88)

[1] Subjects who could not be reached at 2 weeks were maintained in the study and were eligible for 2-month follow-up.

[2] Those who were not able to be reached at either 2 weeks or 2 months were not included in the 6-month follow-up interview.

Sample Description. Participants averaged 46.18 years of age (±12.24). The majority were Caucasian (89%). Almost half of the participants (43.5%) had a college degree or higher. Twenty-three percent of women had a cancer diagnosis and 12% had previously used a risk assessment (Table 2). A series of two-tailed t tests and chi-square analyses were performed for continuous and categorical background variables, respectively, at baseline, in order to detect differences between the two study groups. Women in the enhanced group were older than women in the standard group (t (185) = 2.27, $p < .05$; enhanced: $M = 48.09$, $SD = 11.55$; standard: $M = 44.07$, $SD = 12.70$), and women in the enhanced group were less likely to participate in a risk assessment program than women in the standard group (t (184) = 2.59, $p < .05$; enhanced: $M = 3.86$, $SD = 1.12$; standard: $M = 3.43$, $SD = 1.14$). In addition, more women of average risk were included in the standard group than in the enhanced group ($\chi^2 = 4.57$, $p < .05$). As a result, all analyses were conducted separately for the high- and low-risk status groups and age was included as a covariate.

Table 2. Overall description of the entire sample ($N = 279$)

Variable	Frequency or mean	Percentage or standard deviation
Age	46.32 years	12.28 years
Education		
Some high school	10	4%
High school grad	65	25.5%
Some college	69	27%
College grad	69	27%
Postgraduate	42	16.5%
Race/ethnicity		
Asian	2	1%
African American	14	5%
Hispanic	3	1%
Native American	4	2%
Caucasian	227	89%
Other	6	2%
Reason for calling CIS		
For breast cancer risk information	208	76%
For ovarian cancer risk information	32	12%
For both breast and ovarian cancer risk information	34	12%
Cancer diagnosis		
Yes	64	23%
No	213	77%
Past use of risk assessment services		
Yes	34	12%
No	242	88%

Outcome Analyses

Overview

A series of analyses were conducted to explore the impact of the intervention on the outcome variables of interest, namely, intention to pursue genetic testing, risk-related knowledge, and risk perception. The sample for these analyses included women who had completed the baseline, the 2-week or 2-month or both, and 6-month follow-up interviews. Analyses were conducted to determine the effect of the interventions on those at average or high risk (based on the Gail score) and to explore the role of monitoring attentional style and sociodemographic variables (e.g., age) on the outcome variables of interest. In order to examine the differential effect of the interventions on outcomes of interest, changes in outcome variables (i.e., intention to obtain genetic testing, risk-related knowledge, risk perceptions) from baseline to the 2-week and 6-month follow-up time points were calculated. Then, two-way ANOVA's were conducted: one for each risk status, average and high, with intervention and monitoring group as the independent variables, controlling for age at baseline. For all analyses, the means presented in parentheses are estimated. Last, analyses were conducted to determine the levels of satisfaction of participants.

Intention to Obtain Genetic Testing. As shown in Figure 2, the intervention had a significant impact on intention to obtain genetic testing across the risk categories at the 6-month follow-up ($F(1,71) = 4.09$, $p < .05$). When risk group was considered, the enhanced intervention diminished intention to obtain genetic testing among women at average risk, but increased intention among women at high risk.

Knowledge. Baseline knowledge about breast cancer risk was fairly high for the majority of participants (8 out of the 17 items, 70% or more of the participants had the correct answer; Table 3). Only 1 in 4 women, however, understood that older age at diagnosis was not a determinant of inherited risk or that that the process of genetic testing was much more complex than having a simple blood test. At baseline, when participants were asked without prompts what risk factors they were aware of, 80% indicated "family history," whereas only 12% indicated age. There were no significant impacts on the overall knowledge score between intervention or risk groups.

Monitoring. For both the average and high-risk groups, intervention type had no impact on general or specific knowledge. For the average-risk group, however, at the 6-month follow-up, there was a main monitoring effect for change in general knowledge, where for high monitors general knowledge increased more than for low monitors ($F(1, 73) = 4.16$, $p < .05$; high monitors: $M = 0.49$, $SD = 0.15$; low monitors: $M = -0.01$, $SD = 0.19$; Table 4).

For both the average and high-risk groups, intervention type had no impact on risk perceptions. Among women at average risk, however, at the 6-month follow-up, there was a main monitoring effect for risk perceptions for breast cancer, where high monitors experienced an increase in risk perceptions for breast cancer when compared with low monitors ($F(1, 67) = 7.06$, $p < .05$; high monitors: $M = 0.24$, $SD = 0.14$; low monitors: $M = -0.38$, $SD = 0.19$; Table 5). No significant effects were found at the 2-week and 2-month follow-ups.

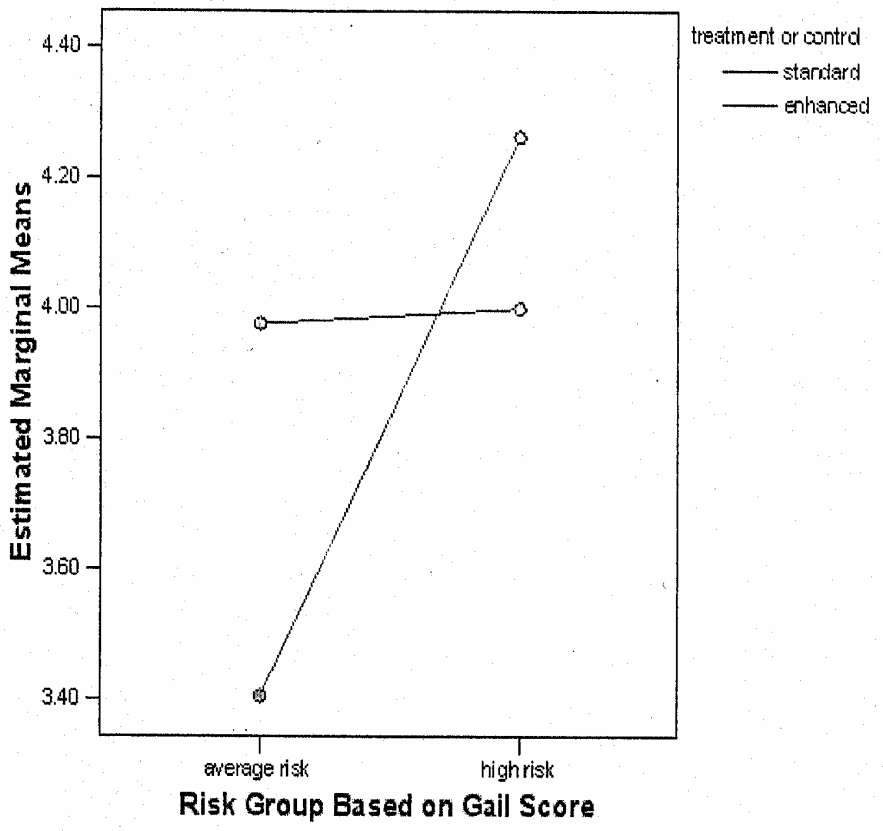

Figure 2. Means of intention to pursue genetic testing at 6 months after call to CIS: Interaction of intervention and risk groups.

Satisfaction With the CIS. The overall satisfaction (intervention group $M = 4.39$; standard care $M = 4.49$) with the CIS was relatively high (5 was the highest score possible), with no significant differences between intervention groups or monitoring styles at the end of the intervention or at the follow-up interviews (Table 5).

Discussion

This study evaluated a novel, theory-based approach to help guide women in making informed decisions about pursuing risk assessment options available to them. Our findings suggest that women at average risk for breast cancer who received the educational intervention reported decreased intention to obtain genetic testing at 6-month follow-up compared with women who received the standard intervention, while women at high risk were more likely to report intention to obtain genetic testing. Given the limited number of qualified genetic counseling programs and the need for women to understand their own familial risk in making decisions about

Table 3. Baseline knowledge and attitudes

Item	Correct response	
	N	(%)
Many women get breast cancer without known risk factors	270	(91)
1 in 8 women will develop breast cancer in their lifetime	251	(85)
Women over 50 are more likely to get breast cancer than younger women	209	(71)
A woman without BRCA 1 & 2 still can get breast or ovarian cancer	196	(66)
Early detection means a greater chance of surviving breast cancer	290	(98)
Women over 40 should have mammograms at least every 2 years	222	(75)
A woman whose mother was diagnosed at age 69 is considered to be at high risk	78	(26)
A woman can inherit breast cancer gene mutations from her father	165	(56)
Most women who develop breast cancer do not have a family history of the disease	168	(57)
Ovarian and breast cancer in the same family can be a sign of hereditary cancer	250	(85)
Testing for breast cancer gene mutations can tell a woman if she has breast cancer	171	(58)
Men cannot inherit breast cancer gene mutations	248	(84)
If there are other types of cancer in my family, my risk is higher than average	199	(67)
The process of risk assessment and genetic testing is simple, involving only a physical examination and blood test	65	(22)
One of the advantages of risk assessment is by finding out your risk it can help you make decisions about risk reduction options, such as surgery and medications	278	(94)
There is no real disadvantage to pursuing risk assessment and genetic testing	162	(55)
A woman who develops breast cancer at an early age is more likely to have an inherited breast cancer	159	(54)

genetic counseling, this is an important step in the appropriate use of public health services. The intervention was designed to help women understand their own risk and the complexities of genetic testing so that decisions about future actions would be more informed (Wang, Gonzalez, Milliron, Strecher, & Merajver, 2005; Wang & Miller, in press).

Of interest, overall and specific knowledge about breast cancer risk, inherited patterns, and the process of risk assessment and genetic counseling were not

Table 4. Monitoring and perceived risk for breast cancer among women of average risk

	Perceived risk			
	Baseline		6-month follow-up	
	M	*SD*	*M*	*SD*
Low monitors	3.84	1.03	3.48	0.87
High monitors	3.67	1.03	3.91	1.98
Total	3.73	1.03	3.76	0.96

significantly impacted by the intervention. Although there might have been a ceiling effect due to the fairly high levels of knowledge at baseline, it is unclear why we did not see significant improvements in knowledge about the importance of early onset of disease and the misconception that genetic testing is a simple process including only a physical exam and blood test. Almost one-half of the sample did not think there was any real disadvantage to pursuing risk assessment/genetic testing. In future work, it will be important to explore whether knowledge levels can be modified if the measures are designed to assess more sensitively the breadth of cognitions related to understanding inherited disease and the complexity of risk assessment and genetic testing.

Consistent with prior research, the study findings also support the premise that high monitors exhibit a signature informational processing style characterized by heightened perceived risk and susceptibility and greater information seeking (e.g., Fang et al., 2003; Rees & Bath, 2000; Schwartz et al., 1995). At the 6-month follow-up, high monitors reported greater increases in risk-related knowledge and in their own perceptions of risk compared with low monitors among women at average risk. These findings are relevant to the design and evaluation of future health

Table 5. Satisfaction* with CIS information service

	Satisfaction					
	Baseline		2-week follow-up		6-month follow-up	
	M	*SD*	*M*	*SD*	*M*	*SD*
Intervention type						
Standard group	4.65	0.68	4.51	0.75	4.51	0.64
Enhanced group	4.63	0.57	4.37	0.84	4.38	0.86
Total	4.64	0.62	4.44	0.79	4.44	0.77
Monitoring style						
Low monitors	4.57	0.69	4.35	0.88	4.39	0.81
High monitors	4.66	0.58	4.46	0.75	4.47	0.77
Total	4.61	0.64	4.40	0.83	4.43	0.79

*Assessed on a 5-point scale, 1 being not at all, 5 being very much.

communications that match communication protocols to monitoring attentional style, as well as to risk status. There is a growing body of literature that suggests that matching to monitoring style can enhance the efficacy of health communications (e.g., Miller, Fang, Diefenbach, & Bales, 2001; Williams-Piehota, Pizarro, Schneider, Mowad, & Salovey, 2005; Williams-Piehota, Schneider, Pizarro, Mowad, & Salovey, 2003). For high monitors, it is important to provide messages that include detailed, but reassuring, information about cancer risk as well as strategies or means of reducing risk (Miller, 1995). On the other hand, low monitors display a cognitive–emotional profile characterized by less knowledge, and an underestimation of their vulnerability for disease (Lerman, Schwartz et al., 1996; Miller, Fang, Manne, Engstrom & Daly, 1999; Miller & Kruus, 1993). They are consequently less likely to engage in health-protective behaviors in the cancer risk context (e.g., Jacob, Penn, Kulik, & Spieth, 1992; Miller et al., 1996). This is especially true among women at average risk, since low monitors have a lower threshold for seeking detailed information about potential health risks. They may benefit from minimal information, particularly when no action is required. Future research is required to evaluate whether tailoring messages to monitoring information-processing styles is more effective in facilitating informed decision making, especially among women at average risk. Indeed, there is evidence that tailoring messages to personal risk among women at familial risk for breast or ovarian cancer can significantly improve risk-related knowledge and diminish overestimation of genetic risk (Skinner et al., 2002).

There were a number of study limitations. The sample was drawn from women proactively calling the NCI's CIS and, therefore, were more likely to be information seekers. Although the findings support a positive relationship between actual risk and seeking risk counseling, it is difficult to determine which specific aspects of the intervention may have had this impact. The initial accrual rate was reasonable, especially for a study introduced at the end of usual service, although we did face challenges in retaining subjects across the 6-month follow-up. The intervention was lengthy for this service environment (required approximately an additional 20–30 minutes for the baseline assessment and educational intervention). Although those who remained in the study were quite satisfied with the service, we suspect that some participants were not able to make the commitment of time over the follow-up interviews. Women who were lost to follow-up reported higher perceived risk at baseline, thereby limiting the generalizability of the findings. Another important challenge was the number of follow-up time points. We used the 2-week follow-up to collect actual risk and monitoring style assessments to reduce participant burden at baseline, given that these variables were not used to tailor the intervention. It may not have been necessary to conduct follow-ups at three time points since the main effects were seen at 6 months.

The main effects of the study were found at 6 months, which is consistent with the time it may take to assimilate and consider such weighty issues. Although the findings support a positive relationship between actual risk and seeking risk counseling, it is difficult to determine which specific aspects of the intervention may have had this impact. It is also important to note that the outcomes (e.g., undergoing genetic risk assessment) were self-reported. Last, the study is limited to the extent that the sample does not adequately represent minority populations that would permit additional subanalyses. Fear about the potential for discrimination among minority populations raises concerns about whether there will be further disparities in health care brought about with advancing genetic technologies (Schulz, Caldwell, & Foster,

2003). Therefore, future steps should be taken to specifically target minorities to better understand barriers to receiving appropriate risk-related care.

Conclusions

As advancements are made in the science of breast cancer risk, the information gained needs to be translated to help women assess their own risk and to facilitate the decisions to take needed self-regulatory actions to protect their health. Our findings showed that the educational intervention created a more realistic perception of risk among both average- and high-risk women indicated by their intention to seek genetic testing. Average-risk women may need more up-stream, in-depth resources to educate them about for whom genetic testing and assessment are appropriate. Further, by being informed about the limitations of genetic testing, they can have accurate expectations about what is involved in genetic risk assessment and what kind of feedback it provides.

The intervention was not tailored based on risk status or monitoring style. Our findings suggest that there would be value in developing and evaluating tailored programs on these two dimensions. Women in the education group who were high monitors were more likely to increase their knowledge and risk perceptions. Future efforts could triage women by monitoring style and tailor the educational messages accordingly. Different messages may have been needed to boost the "attention" of the low monitors in this study. It is clear that this type of in-depth intervention can be delivered in a service environment. The majority of women indicated high levels of satisfaction with the CIS, especially with such complex and difficult issues as risk assessment and genetic testing. The CIS and other public education service programs can play an important role in the educational process and serve as an initial triage to assist in the decision-making process related to risk assessment and genetic testing, especially in light of the limited educational resources available through primary care and public health programs.

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Running Head: DECISION MAKING IN *BRCA1/2* TESTING

Enhanced Counseling for Women Undergoing *BRCA1/2* Testing: Impact on Subsequent Decision Making About Risk Reduction Behaviors

Suzanne M. Miller, Ph.D., Senior Member Population Science and Director of Behavioral Medicine, Fox Chase Cancer Center
Pagona Roussi, Ph.D., Assistant Professor, Psychology Department, Aristotle University of Thessaloniki, Thessaloniki, Greece
Mary B. Daly, MD, Ph.D., Senior Member Population Science, Fox Chase Cancer Center
Joanne S. Buzaglo, Ph.D., Senior Scientific Associate, Behavioral Medicine, Fox Chase Cancer Center
Kerry Sherman, Ph.D., Assistant Member, Behavior Medicine, Fox Chase Cancer Center*
Andrew K. Godwin, Ph.D., Director, Clinical Molecular Genetics Laboratory, Fox Chase Cancer Center
Andrew Balshem, B.A., Manager, Population Studies Facility, Fox Chase Cancer Center
Margaret E. Atchison, Health Educator, Behavioral Medicine, Fox Chase Cancer Center

Address requests to Suzanne M. Miller, Ph.D., Fox Chase Cancer Center, 333 Cottman Avenue, Suite P1096, Philadelphia, PA 19111.

* Currently Lecturer, Department of Psychology, Macquarie University, Sydney

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ABSTRACT

We evaluated the impact of an enhanced counseling intervention, designed to promote well-informed decision making for follow-up risk reduction options for ovarian cancer, among high-risk women undergoing *BRCA1/2* testing (N = 77). Following standard genetic counseling, participants received either an Enhanced Counseling session -- designed to help participants anticipate their reactions to possible test outcomes and plan for post-result consequences -- or a General Health Information control session. One week after disclosure of test results, women in the enhanced counseling group experienced a greater reduction in avoidant ideation, suggesting more complete processing of risk feedback. At the six month follow-up, intervention subjects reported seeking out more information about prophylactic oophorectomy, and were more likely to have actually undergone preventive surgery. The results indicate that the use of enhanced counseling can play an important role in decision making about risk reduction behaviors following *BRCA1/2* testing.

Keywords: *BRCA1/2* genetic *risk*, prophylactic ovarian surgery, enhanced counseling intervention

Recent advances in molecular genetics have led to the discovery of a number of genes associated with an inherited susceptibility to cancer. Building on the results of genetic linkage analysis, investigators have identified two tumor suppressor genes, *BRCA1* and *BRCA2*, which when altered, can significantly increase susceptibility for breast and ovarian cancer. *BRCA1/2* carriers have a lifetime risk of breast cancer which ranges from 40% to 85%, and a lifetime risk of ovarian cancer which ranges from 16% to 60% (Antoniou, Pharoah, Narod, et al., 2003; Easton, Ford, & Bishop, 1995; Schrag et al., 1997; Struewing, Hartge, Wacholder et al., 1997; Whittemore, Gong, & Itnyre, 1997). Among women faced with increased genetic risk for ovarian cancer, prophylactic oophorectomy and increased surveillance for ovarian cancer have been associated with a 90 to 95% reduction in ovarian cancer incidence, as well as a 50% reduction in new breast cancers (Kauff, Satagopan, Robson et al., 2002; Rebbeck, Levin, Eisen et al., 1999; Rebbeck, Lynch, Neuhausen, et al., 2002; Scheuer, Kauff, Robson, et al., 2002). In light of these findings, the National Comprehensive Cancer Network (NCCN) guidelines for the management of hereditary susceptibility to breast and ovarian cancer recommend consideration of prophylactic surgery in women with known deleterious mutations on a case-by-case basis, with a full discussion of the risks and benefits (Daly, 1999).

For women with a putative family history of ovarian and/or breast cancer, genetic testing for *BRCA1/2* mutations offers the promise of reducing uncertainty

surrounding their risk status, thus enabling them to make more informed decisions about whether or not to undergo prophylactic surgery (Hallowell & Richards, 1997; Hurley, Miller, Costalas, Gillespie, & Daly, 2001; Marteau & Lerman, 2001). Yet, the few studies that have examined the effects of genetic testing on risk reduction decisions have found that a significant proportion of eligible women do not take any action following feedback of their *BRCA1/2* carrier status (Botkin, Smith, Croyle, et al., 2003; Lerman, Hughes, Croyle, et al., 2000; Meijers-Heijboer, Brekelmans, Menke-Pluymers, et al., 2003; Meijers-Heijboer, Verhoog, Brekelmans, et al., 2000; Miller, Fang, Manne, Engstrom, & Daly, 1999; Schwartz, Kaufman, Peshkin, et al., 2003; Tinley, Houfek, Watson, et al., 2004). Among women with indeterminate results, fewer than 5% choose prophylactic oophorectomy (Botkin et al., 2003; Schwartz et al., 2003). Among carriers, women whose families are affected by cancer, women who are themselves affected by cancer, and women who perceive their personal risk for cancer as high are more likely to have preventive oophorectomy (Meijers-Heijboer et al., 2000, 2003; Schwartz et al., 2003). Finally, carriers who opt for preventive oophorectomy are older (Botkin et al., 2003; Scheuer et al., 2002; Schwartz et al., 2003), and thus are more likely to have completed child-bearing

Standard preparation for genetic testing involves the provision of personalized information regarding risk; presentation of the benefits, limitations, and risks of genetic testing; information regarding the meaning of the result; and

feedback about the options available for risk reduction and surveillance (Wang, Gonzalez, & Merajver, 2004). However, the information that is provided is complex and probabilistic and may be difficult for women to process (Peshkin, DeMarco, Brogan, Lerman, & Isaacs, 2001). Further, decisions about management options cannot be enacted until the results of genetic testing are known, and therefore decisions need to be integrated over time. Hence, existing genetic testing counseling approaches may not adequately prepare women for the sequence of decision making challenges and risk-related choices they may face (van Roosmalen, Stalmeier, Verhoef, et al., 2004).

A growing need in this area is therefore not just to document the uptake of risk reduction regimens after genetic testing, but to design more effective ways of preparing women to receive these results, in order to maximize information processing under uncertainty and promote informed decision making (NIH, 1995; O'Connor, Fiset, DeGrasse, et al. 1999; Shoda, Mischel, Miller, et al., 1998; Wang et al., 2004). One study of women undergoing *BRCA1/2* testing found that women who received a decision aid -- consisting of a brochure and a video providing information on screening and preventive surgery and their respective physical, emotional and social consequences -- expressed greater intentions to have preventive surgery compared to women who received standard counseling alone (van Roosmalen et al., 2004).

Guided by the Cognitive-Social Health Information Processing (C-SHIP) model (Miller, Shoda, & Hurley, 1996; Shoda et al., 1998), we developed and evaluated an enhanced counseling intervention to facilitate the personal processing of genetic testing information, both cognitively and affectively, among at-risk women about to undergo *BRCA1/2* testing. The C-SHIP posits that individuals are characterized by a relatively stable structure of cognitions and affects that are likely to become activated when encountering a health-threatening situation. These cognitions and affects, in turn, shape intentions to take protective action, as well as their actual implementation. However, individuals are not necessarily aware of the kinds of cognitions and affects they are likely to experience over the course of coping with a health challenge (Loewenstein, 2005). This is particularly the case in response to unfamiliar and unfolding situations, such as *BRCA1/2* testing, where subsequent decisions are preference-based and need to be made as new and probabilistic information (e.g., the genetic test result) becomes available.

The purpose of the enhanced counseling intervention was to activate and "pre-live" these likely cognitive-affective reactions, in a supportive environment, so that the woman could better self-assess and strategically plan for each potential test result scenario (Miller et al., 1996). In a randomized controlled trial, enhanced counseling was implemented immediately after standard genetic counseling, prior to blood donation. The efficacy of the enhanced counseling

intervention was directly compared to standard care plus a General Health Information counseling session that provided generic health information and was matched to the intervention for time, attention, and format.

Consistent with the C-SHIP model, we hypothesized that: (1) women who had received the enhanced counseling intervention would experience a greater reduction in risk-related avoidant ideation after receipt of the genetic test result than women in standard care, reflecting a more complete processing of their *BRCA1/2* carrier status; (2) women who had received the enhanced counseling intervention would be more likely than women in standard care to manage genetic testing feedback by subsequently seeking information about their risk reduction options, since they should be more primed to engage in anticipatory planning; (3) women in enhanced counseling would be more likely than women in standard care to actually undergo prophylactic oophorectomy, since they should be more prepared to implement their action plans; and (4) independent of intervention, test result and greater perceived risk would predict information seeking and uptake behaviors, along with background factors (i.e., family and personal history of cancer, age, and education).

Method

Participants

Participants were recruited from the well-established Family Risk Assessment Program (FRAP) at Fox Chase Cancer Center (FCCC) and four

affiliated Fox Chase Network hospitals. Recruitment occurred between May 1998 and October 2000. Eligibility criteria included: 1) age $\geq$ 21; 2) a family history consistent with a possible hereditary pattern of breast or ovarian cancer; 3) ability to communicate with ease in English; 4) competency to provide informed consent; 5) reasonable access ($\leq$ 2 hour commute) to participating sites; and 6) women with at least one ovary intact. Of the 135 women originally recruited, seven women decided not to donate blood for genetic testing and thus were not included in the analyses. Fifty one women who had provided baseline data dropped out or were not reachable for follow-up, resulting in a final sample of N = 77. Drop-out rates were equivalent in the two study groups. The study was approved by the Institutional Review Board at FCCC.

Procedures

Eligible participants were recruited during the first self-initiated telephone contact with FRAP (baseline). Consenting participants were randomized to either the intervention or control group and were mailed baseline questionnaires to complete at home and return at their initial FRAP visit, one week later. At that visit, they attended a Standard Cancer Education group session (involving education on average risk for breast and ovarian cancer, factors contributing to elevated risk, hereditary patterns, general screening recommendations, and available preventive options). Two weeks later, participants returned to FRAP for an individual counseling session with a certified Genetic Counselor or nurse

educator to review and expand the family pedigree; to identify potential hereditary patterns of cancer; and to discuss the potential limitations, benefits and risks of genetic testing. This was immediately followed by the receipt of: 1) a Cognitive-Affective Preparation Enhanced Counseling Intervention individual session; or 2) a General Health Information control session. Participants were randomly allocated to one of the two conditions. At the end of the session, participants were given the option to donate blood for genetic testing, or to give blood for a national registry, without being notified of the results. In order to eliminate financial barriers to participation, the cost for genetic testing was included in the research funds.

Prior to receiving the test result, participants underwent a pre-disclosure session (on average 17 weeks after blood donation) to discuss issues addressed in the individual counseling session and to reconfirm the decision to obtain the test result. Receipt of the test result involved a disclosure session, during which the decision to receive the result was reconfirmed, the test result was communicated, and its implications regarding risk-reduction and surveillance behaviors were discussed. Participants received a positive, a negative, an uninformative, or an incomplete test result. A positive test result was given when a known deleterious mutation was detected. A negative test result was given when a deleterious mutation was not detected in the participant, but had been detected in the family. An uninformative test result was given in one of two instances: (1) when a

deleterious mutation was not detected in the participant and a mutation in the family had not been identified as yet (indeterminate), or (2) when a mutation whose significance was unknown had been detected (inconclusive). Included in this category were also those who received an incomplete test result, which was given when only one of the two *BRCA* genes was sequenced and were negative.

Enhanced Counseling Intervention. A Health Educator led the individual session, lasting approximately 45 minute. The intervention was based on the premise that receipt of genetic test results would activate relatively stable cognitive-affective structures. These structures influence decision-making but are not necessarily logical nor under cognitive control, making them difficult to access. The intervention was designed to make these likely reactions more accessible during the decision-making process by pre-living the main outcome scenarios of genetic testing (i.e., receipt of positive, uninformative, or negative test results). Preliving was achieved through the use of a role-play format in which the counselor and the woman realistically enacted and considered each of the possible test outcomes to heighten self-awareness on the part of individual, in order to facilitate subsequent preparatory planning around available risk reduction options.

After an introduction, the Health Counselor and participant enacted the situation of: 1) obtaining a positive mutation; 2) a negative mutation; or 3) an uninformative test result. The order of presentation of the genetic testing outcome

scenarios was randomly varied. All scenarios were "pre-lived" in detail, as if they were really occurring, focusing on the meaning of the results for the individual's risk status, risk reduction options, family and life (e.g., insurability, employment). Still within the role structure of the "getting-the-results" experience, the individual's thoughts and feelings with regard to the results were sensitively probed to enhance her self-assessment of her own reactions and priorities. Participants thus were encouraged to anticipate the thoughts and feelings that they might have about the aspects of their life that might be affected by the genetic test result, the values and goals activated by these thoughts and feelings, and the implications forrisk reduction, as well as for related preparatory plans and actions.

General Health Information. This individual session, led by a Health Educator, also lasted 45 minutes and was designed to control for the extra time and attention provided to participants in the enhanced counseling condition. Participants in this condition received and discussed current recommendations for general health (e.g., diet, exercise, alcohol use, smoking) and were encouraged to discuss their own attitudes, beliefs, and feelings about these topics in the same type of role-play format used in the intervention condition.

Measures

Background Variables. Background variables, obtained at baseline, assessed family and personal history of breast and ovarian cancer, as well as sociodemographic variables (i.e., education, age, ethnicity, marital status, number

of children, and menopausal status). In addition, trait anxiety was assessed at baseline using the 20 item Spielberger Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1983), a well validated self-report instrument. Trait anxiety was included to control for background levels of anxiety, which can affect the ease of accessibility of particular cognitions and affects (Leventhal & Patrick-Miller, 2000).

Perceived risk. Perceived risk for ovarian cancer was assessed at baseline and one week after disclosure of genetic test result (Hallowell, 1998). Participants were asked to estimate their perceived risk for ovarian cancer by indicating the degree to which they believed they were the kind of person who was likely to get ovarian cancer, on a scale from 1 ("not at all") to 5 ("extremely"). For the analyses, the measure was dichotomized to form two groups, a high and a low perceived risk group.

Avoidant Ideation. The degree to which participants processed the risk-related information provided to them was assessed at baseline and one week after the disclosure of genetic test results, using the eight-item avoidant ideation subscale of the Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979), a well-validated self-report instrument. The Impact of Events Scale measures the subjective impact experienced as a result of a specific event. It was based on the clinical observation that there are two major response sets to stressors, intrusion and avoidance. Avoidant ideation has been associated with "denial of the meaning

and consequences of the event, behavioral inhibition, and awareness of emotional numbness (Horowitz et al., 1979, 1981). When people feel threatened, it elevates their focus on the event, which prompts them to make effortful avoidance attempts that can lead to emotional numbing. Participants rate the frequency of avoidant symptoms (e.g., "I tried not to think about it; I avoided letting myself get upset when I thought about it or was reminded of it; My feelings about it were kind of numb; I tried not to talk about it.") on a weighted four-point scale. Avoidant ideation was mildly elevated at baseline compared to published norms ($\underline{M}$ = 8.64, $\underline{SD}$ = 8.46), with an internal reliability (Cronbach's alpha) of 0.85.

Information Seeking about Prophylactic Oophorectomy. At baseline, and at six months post-feedback of genetic test results, participants were asked whether or not they had sought information from their health practitioners with regard to prophylactic oophorectomy.

Risk Reduction Behaviors: Uptake of Prophylactic Oophorectomy. Six months post-feedback of genetic test results, participants were asked to indicate whether or not they had undergone prophylactic oophorectomy.

Results

Sample Description

Table 1 presents demographic and medical information for both the control and intervention groups. The vast majority (95%) of participants chose to donate blood for testing and registration, as well as to receive their test result.

The high percentage of women who opted to donate blood probably reflects the lack of a financial burden, since it was covered by research funds as well as the fact that these women represented a highly motivated group of self-referred individuals. Seventeen percent of the women tested positive, 4% negative, and the majority (79%) received an uninformative test result. These results are consistent with our experience in the FRAP program, particularly when the person seeking genetic testing is unaffected and/or is the first person in the family to be tested. Uninformative test results may eventually become informative as additional family members undergo testing. Women who remained in the study across all time points were more likely to be carriers, $\chi^2 = 7.05$, $p < .05$, and had lower trait anxiety, $t\ (114) = 2.49$, $p < .05$. A series of two-tailed *t*-tests and *chi*-square analyses were performed at baseline for the continuous and categorical background variables, in order to detect differences between the two study groups. Women in the enhanced counseling intervention were found to be higher in trait anxiety than women in the attention control group ($t\ (69) = 2.18$, $p < .05$; Enhanced: $M = 34.76$, $SD = 9.39$; Control: $M = 30.05$, $SD = 8.84$). As a result, this variable was included in all subsequent analyses as a background variable.

Avoidant Ideation

The change in avoidant ideation from baseline to one-week post-feedback of genetic test results was calculated, and a univariate analysis of covariance (ANCOVA) was conducted with test result, disease status, and intervention

condition as the independent variables and change in stress-related avoidant ideation as the dependent variable, controlling for trait anxiety. Interaction terms between condition and test result and condition and disease status were also included. Women in the enhanced counseling group experienced a greater reduction in avoidant ideation than women in the general health information group (F (1, 53) = 5.11, $p < .05$; Enhanced: M = -4.72, SD = 10.30; Control: M = -0.19, SD = 5.83). No other effects were found.

Information Seeking and Behaviors

Univariate tests were conducted first to test the relationship between risk reduction decisions on the one hand, and intervention group, as well as background factors, test result, risk perception (post-feedback), and avoidant ideation (post-feedback), on the other hand. Chi-square analyses were performed for categorical variables and t-tests were performed for continuous variables. Variables that were significant at the univariate level were included as predictors of risk reduction information-seeking and decisions in a series of logistic regression analyses, with backward variable deletion. Two dummy variables, each one with two levels (yes/no), one for positive test result and one for uninformative test result, were used to account for test result, a qualitative variable with three levels.

Information Seeking: Prophylactic Oophorectomy

Univariate tests showed that receipt of enhanced counseling predicted greater information-seeking about prophylactic oophorectomy ($\chi^2 = 11.11$, $p < .001$). Specifically, 68% of women in the intervention group sought information, as compared to 26% of women in the control group. In addition, information seeking was greater for women affected with cancer ($\chi^2 = 6.14$, $p < .05$), and with greater perceived risk ($\chi^2 = 9.67$, $p < .01$). Test result was also a predictive factor: 90% of women who tested positive inquired about undergoing a prophylactic oophorectomy, compared with 40% of those with an uninformative test result, and none with a negative test result, ($\chi^2 = 11.00$, $p < .01$). The final logistic regression model included intervention group, disease status, and perception of risk ($\chi^2 = 20.34$, $p < .01$), such that women in the enhanced counseling group, women affected with cancer, and women with higher perceived risk were more likely to have sought out information about prophylactic surgery (Table 2).

Uptake: Prophylactic Oophorectomy

At six months following receipt of the test result, eleven women (14%) had undergone prophylactic oophorectomy. Univariate tests showed that participation in enhanced counseling predicted uptake of oophorectomy ($\chi^2 = 5.87$, $p < .05$). Specifically, 28% of women in the intervention group had undergone preventive surgery, as compared to 6% of women in the control group. Being affected with cancer ($\chi^2 = 6.18$, $p < .05$), test result ($\chi^2 = 16.12$, $p < .001$), and lower education level ($\chi^2 = 8.34$, $p < .01$) were also predictors. Specifically,

among carriers, 60% had undergone prophylactic oophorectomy. This compared with 9% among women with an uninformative result and 0% among women with a negative result. The final logistic regression model for proceeding with surgery included intervention group, whether or not one had an uninformative result, and level of education ($\chi^2 = 20.19$, $p < .001$). Women in the enhanced counseling group were more likely to have undergone prophylactic oophorectomy, whereas women with an uninformative result and women with college education were less likely to have had undergone an oophorectomy (Table 3).

Discussion

We predicted that the opportunity to anticipate and pre-live one's cognitive, affective, and behavioral reactions to a genetic test result would facilitate the individual's processing of the information provided, leading to lower avoidant ideation and more action-oriented decisions following receipt of the genetic test result (Miller et al., 1996). The intervention included the vivid acting-out of the disclosure of results situation as if it were occurring *in vivo*, an exploration of the individual's personal reactions to these scenarios, and a formulation of plans to deal with possible outcomes (Shoda et al., 1998). Our results confirmed that women who had received the intervention subsequently experienced lower threat-related avoidant ideation, suggesting that the intervention was successful in facilitating information processing, including the potential consequences and management of the genetic test result (Patenaude,

2005), through circumventing avoidance tendencies (Janis, 1967; Janis & Leventhal, 1967). For example, individuals were asked to consider what particular aspects of genetic testing feedback were difficult for them to think about. Prompting individuals to pre-live their cognitive-emotional responses in a guided, systematic fashion may be important, given that individuals are not particularly good at coping with the interfering effects of unanticipated affect (Loewenstein et al., 2001; Loewenstein, 2005; Rothbaum, Kozak, Foa & Whitaker, 2001; Ubel, 2005).

Prior work on genetic testing and affect has focused mainly on general or cancer-specific distress (Braithwaite, Emery, Walter, Prevost, & Sutton, 2004). Intrusive ideation entails the extent to which individuals obviously focus on, obsess about, and are absorbed in repetitive thoughts about a threat or challenge (e.g., McInerney-Leo et al., 2004; Schwartz, Lerman, Miller, et al., 1995). While intrusive ideation can interfere with effective risk information processing, less is known about how avoidant ideation impacts the response to risk counseling. Our results suggest that it may also be meaningful to consider the extent to which the individual actively avoids, distracts from, or disengages from risk-related information in order to reduce uncomfortable intrusive ideation (Patenaude, 2005).

Consistent with a deeper processing of the consequences of the genetic test result, women who received the enhanced counseling intervention were more

likely to have inquired about prophylactic surgery. Our results are consistent with a recent study that looked at the impact of a decision aid on preferences for prophylactic oophorectomy among women being tested for a *BRCA1/2* mutation (van Roosmalen et al., 2004). In terms of actual behavior, our results showed that over four times as many women underwent prophylactic surgery in the intervention group as in the control group. Although the follow-up period was only six months, previous research suggests that the majority of women make their decisions about oophorectomy uptake shortly after the receipt of the genetic test result (Kauff et al, 2002). However, in future research, it will be important to assess behavior over longer time points.

Recent data suggest that preventive oophorectomy is associated with reduced risk not only for ovarian cancer, but also for breast cancer (Kauff et al., 2002; Scheuer et al., 2002; Rebbeck et al., 1999). To the extent that early adoption of risk-reduction strategies, such as prophylactic oophorectomy, has a significant impact on lowering morbidity, interventions that help women process information about these strategies may be useful. The personalized processing activated by our intervention may have allowed the individual to develop more accurate and realistic expectations of her treatment options over time, and to adopt a more informed decision making approach (O'Connor, Jacobsen, & Stacey, 2002). We also found that women with heightened perceptions of vulnerability to ovarian cancer were more likely to have inquired about

prophylactic surgery. High perceived risk has been associated with risk reduction behaviors in other work (Isaacs, Peshkin, Schwartz et al., 2002; Schwartz et al., 2003) and indicates that feelings of personal vulnerability can motivate controlling actions (Miller et al., 1999). In future research, we will need to more systematically evaluate, in a fine-grained fashion, how preliving modifies information processing with respect to the individual's self-construals/risk perceptions, expectancies/beliefs, values/goals, affects/emotions, and self-regulatory strategies (Miller et al., 1996).

Test result and education were also significant predictors of oophorectomy uptake, with carriers and women without a college education being more likely to undergo prophylactic surgery. The finding that carriers opt for prophylactic surgery in higher percentages than women with an uninformative or a negative result has been observed in a number of studies (Scheuer et al., 2002; Schwartz et al., 2003; Meijers-Heijboer et al., 2003; Meijers-Heijboer et al., 2000; Botkin et al., 2003; Lerman et al., 2000). However, the effect of education on preventive surgery has not previously been reported. Although this finding needs to be replicated and further explored, it may be that women with less education prefer more definitive and control-oriented methods that do not require continuous surveillance and ongoing coping (Meiser, Tiller, Gleeson, et al., 2000) Further, the doctor-patient relationship and/or communication pattern may vary based on patient level of education (e.g., Keating et al., 2003; Degner et al., 1997)

There are a number of limitations of the present study. First, the data regarding prophylactic surgery are based on self-report. Although it will be important in the future to confirm our findings using data collected from medical records, self-reports have generally been found to be reasonably accurate (King, Rimer, Trock, Balshem, & Engstrom, 1990). In addition, women who were lost to follow-up were more likely to be noncarriers and to be characterized by lower trait anxiety, thereby limiting the generalizability of the findings. These results make sense since noncarriers are less threatened and therefore less interested in participation over time. In future research, it will be important to develop strategies to reduce attrition among these groups. Further, the large majority of women donated blood. This finding probably reflects the fact that the cost of genetic testing was covered by research funds, as well as that the study participant pool represented a highly motivated, self-referred group. Although cost of genetic testing was not an issue in the present study, there is no reason to believe that the impact of the intervention would have been different if the cost were transferred to the individual. In addition, these concerns will be less relevant as genetic testing becomes more readily available, and costs of testing are reduced.

In conclusion, our results indicate that the process of genetic counseling and testing can affect information seeking and management choices about ovarian cancer risk. Consistent with the cognitive social model, women who were provided with the opportunity to fully process, anticipate, and plan for the impact

of testing feedback were more likely to subsequently seek out information about, as well as to undergo, prophylactic oophorectomy. In addition, women with uninformative results were less likely to opt for prophylactic surgery, as would be expected. Further, consistent with prior research, women with a personal history of cancer -- as well as women with higher perceptions of personal risk for ovarian cancer -- were more likely to seek out information about their risk reduction options. The present results add to the literature on counseling strategies for high risk women, and suggest that the explicit activation of the individual's cognitive-affective processing system may be an important adjuvant to existing approaches to the design of decisional tools and aids (Green, Peterson, Baker, et al., 2004). Future investigations need to consider other outcomes related to the decision making process, including decisional conflict (e.g, O'Connor, Fiset, DeGrasse et al., 1999; O'Connor, 1995) and decisional regret (e.g., Brehaut, O'Connor, Wood et al., 2003).

Implications for Practitioners

The findings raise several implications for patient-provider communication in the context of genetic testing. Patients not only need to understand the meaning of the test result for them personally, but also need to be able to weigh their own personal reactions and priorities in terms of the risk management options available to them. To better accomplish this goal, the results

highlight the importance of genetic counseling approaches that incorporate a component that allows the participant to "pre-live" the receipt of test results.

This approach thus builds on and extends existing counseling approaches, by explicitly priming and bringing into conscious awareness the individual's likely responses and priorities *in vivo*. In this way, threat-related avoidant ideation can be minimized and active coping can be maximized, an important consideration for patient care. It may therefore be useful for oncologists, genetic counselors, and nursesto include psychologists in the health care team to facilitate communication on how best to tailor counseling to individual patient needs and preferences.

The pre-living technique developed here can also be extended to patients who have decided to undergo prophylactic oophorectomy to help them better anticipate and deal with the physical and emotional consequences of surgery (Meiser et al., 2000; Hallowell et al., 2002). Genetic counseling was originally developed in the pre-natal context, following a nondirective approach. However, the use of more directive techniques, such as the pre-living approach tested here, may be increasingly relevant to genetic testing for disease such as ovarian cancer. To the extent that choosing to undergo prophylactic surgery results in lowered rates of disease morbidity, counseling interventions that help women make informed decisions about this issue may be a crucial first step in appropriate preventive care. An important challenge for dissemination will be to explore how

these types of intensive psychosocial interventions can be more readily and practically transported into the clinical setting, given the practical and financial barriers.

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.Table 1
Background Information by Intervention Group

	Control	Enhanced	Total
	N (%)	N (%)	N (%)
Age, years			
> 50	14 (35)	15 (40)	29 (38)
≤ 50	26 (65)	22 (60)	48 (62)
Education			
≥ College	29 (72)	20 (54)	49 (64)
< College	11 (28)	17 (46)	28 (36)
Marital status			
Married	30 (79)	28 (76)	58 (77)
Single	8 (21)	9 (24)	17 (23)
Race			
White	38 (95)	36 (97)	74 (96)
Other	2 (5)	1 (3)	3 (4)
Children			
Yes	29 (81)	29 (83)	58 (82)
No	7 (19)	6 (17)	13 (18)

Table 1 (contd.)

Background Information by Intervention Group

	Control	Enhanced	Total
	N (%)	N (%)	N (%)
Affected with breast cancer			
No	24 (62)	16 (43)	40 (53)
Yes	15 (39)	21 (57)	36 (47)
Genetic test result			
Positive	5 (13)	8 (22)	13 (17)
Negative	3 (7)	- -	3 (4)
Uninformative	32 (80)	29 (78)	61 (79)

Table 2

Logistic Model Predicting Collecting Information about Prophylactic Oophorectomy

	OR	95% CI	*p*
Intervention			
Control (referent)			
Enhanced	4.21	1.09 - 16.31	.04
Disease Status			
Unaffected (referent)			
Affected	4.67	1.14 - 19.15	.03
Risk Perceptions	6.74	1.66 - 27.35	.008

Table 3

Logistic Model Predicting Prophylactic Oophorectomy

	OR	95% CI	*p*
Intervention			
Control (referent)	1.00		
Enhanced	8.33	1.20 – 57.64	.03
Test result			
Definitive (referent)	1.00		
Uninformative	0.11	0.02 – 0.62	.01
Educational Level			
< than college (referent)	1.00		
> than college	0.16	0.03 – 0.83	.03

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PSYCHOSOCIAL DETERMINANTS OF PARTICIPATION IN BREAST CANCER RISK COUNSELING PROGRAMS AND SCREENING REGIMENS AMONG AFRICAN AMERICAN WOMEN

(Heading: Psychosocial determinants of participation)

Kerry A. Sherman, Ph.D.
Assistant Member, Psychosocial and Behavioral Medicine Program
Division of Population Science
Fox Chase Cancer Center
Philadelphia, PA

Suzanne M. Miller, Ph.D.
Senior Member, Division of Population Science
Director, Psychosocial and Behavioral Medicine Program
Director, Behavioral Research Core Facility
Director, Behavioral Center of Excellence in Breast Cancer
Fox Chase Cancer Center
Philadelphia, PA

Sherri Sheinfeld Gorin, Ph.D. [a]
Assistant Professor of Sociomedical Sciences and Epidemiology
Mailman School of Public Health of Columbia University
600 West 168th Street, fourth floor
New York, N.Y. 10032
212-305-1185
Fax: 212-305-9413
E-mail: ssg19@columbia.edu

[a] Address for reprints

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ABSTRACT

Purpose. Since most of the research about the uptake and impact of risk assessment programs has focused on Caucasian women, few data are available to guide the implementation of these programs to specifically address the unique needs of African American women. Further, no published reviews have yet integrated the cognitive-affective and social support constructs that predict participation in breast cancer surveillance among African American women. In this paper, we outline two unifying theoretical frameworks, the Cognitive-Social Health Information Processing (C-SHIP) model and the Social Network model, for understanding genetic risk assessment participation and breast screening behaviors among African American women. These frameworks are applied to a Komen-funded study that is developing and testing a cognitive-affective-social network (CASN) intervention, designed to facilitate interest in breast cancer risk assessment, as well as adherence to breast cancer screening recommendations.

Description of the Study. There are four distinctive cognitive-emotional processes that underlie the information processing of cancer risk information among African American women, including: 1) individuals' self-construals of their risk (i.e., knowledge levels and perceived risk); 2) their expectancies about the benefits and limitations of specific cancer-related actions; 3) their health values (e.g., fatalistic attitudes about cancer); and, 4) cancer-specific emotional distress. The influence of each of the theory-guided units on the uptake of genetic risk assessment and screening participation is reviewed and analyzed. Using the Social Network approach, the effects of social support (i.e., emotional, appraisal, informational, and instrumental support) are examined as further influences on these health-related behaviors.

Results. The results of the literature survey in relation to at-risk African American women suggests five sets of conclusions: First, low levels of breast cancer-related knowledge are pervasive and women tend to underestimate their risk. Risk perceptions do not influence screening behaviors, but accuracy of knowledge is directly associated with screening practices. Further, risk perception is directly related to interest in genetic risk assessment. Second, readiness to participate in breast cancer screening and risk assessment programs is related to holding beliefs that the advantages outweigh the disadvantages. Fatalistic thinking concerning the inevitability of cancer diagnosis is related to poor screening adherence and low levels of participation in risk assessment programs. Third, higher cancer-related worries and fears diminish screening adherence, but facilitate interest in risk assessment participation. Fourth, under routine conditions, high monitors (who are more attentive to health threats) demonstrate increased adherence to screening regimens. Under conditions of high threat (e.g., feedback of an abnormal screening result, awareness of genetic risk for breast cancer), however, high monitors respond with heightened levels of risk-related anxiety and avoidance. Further, high monitors are likely to report increased interest in risk assessment participation. Finally, considerable evidence supports the importance of the social support system (i.e., family, friends, physicians) in enhancing risk assessment decisions and in increasing breast screening adherence.

Implications. We are developing and testing a cognitive-affective-social network (CASN) intervention, designed to facilitate interest in breast cancer risk assessment, as well as adherence to breast cancer-screening recommendations. The CASN intervention is tailored to the specific cognitive and affective profiles of African American women as they make decisions about participating in risk assessment programs and adhering to breast cancer screening regimens. Further, the intervention concomitantly targets the members of the woman's social network, as well as the woman herself. Hence, it should be maximally effective in facilitating informed decision making and adherence.

BREAST CANCER INCIDENCE, MORTALITY AND SURVEILLANCE AMONG AFRICAN-AMERICANS

It is estimated that 203,500 women will be diagnosed with breast cancer in 2002 and 40,000 women will die from the disease (1). Although Caucasians are more likely to develop breast cancer (i.e., 115.5 cases for every 100,000 Caucasian women, compared with 101.5 African American cases), African American women are more likely to die from the disease (2,3). It is well documented that inadequate cancer screening leads to later stage disease (4).

Higher mortality rates among African American women may be due, in part, to the fact that they are less likely to adhere to breast screening recommendations (4, 5), particularly among older women (6, 7), and that they more often delay seeking treatment in the presence of symptoms (8). Incidence of poor mammography adherence is particularly prevalent among low income and underinsured women (9). While breast cancer screening rates among African American women have risen in recent years, they are still below optimal levels (10). Thus, one factor accounting for differential morbidity and mortality rates among African American and Caucasian women may be variations in breast cancer screening adherence, with African Americans more likely to be among the lower income, less educated, and inadequately insured group (11, 12).

In addition to the availability of screening regimens, the recent discovery and identification of the BRCA1 and 2 genes associated with inherited susceptibility to breast and ovarian cancer has led to the implementation of breast cancer familial risk assessment programs. BRCA1/2 mutations account for approximately 5% of breast cancer cases (1), and confer an estimated range from 36-85% lifetime risk of developing breast cancer, and a 16-60% lifetime risk for ovarian cancer (13). Recent investigations of BRCA1/2 mutations in African American

populations have identified similar rates of these mutations as have been previously identified in Caucasian populations (14, 15). Familial risk assessment programs generally entail cancer risk education, personal pedigree feedback, genetic risk assessment for putative hereditary cases, and individualized screening recommendations.

African American women are notably under-represented in familial risk programs, compared with Caucasian women (12,16). Even when African American women participate in these programs, they appear to derive less benefit from their participation compared with Caucasian women. For example, one study (16) found that African American women did not exhibit as large an increase in their levels of pros about risk assessment nor as substantial a decrease in their levels of cons about assessment, versus white women after risk assessment counseling. One explanation for these results is that assessment programs have been created in a generic fashion, failing to consider unique barriers and facilitators to assessment for African American women (12). Since most of the research about the uptake and impact of risk assessment programs has focused on Caucasian women, little data are available to guide the implementation of risk assessment programs specifically addressing the unique needs of African American women. Similarly, although several comprehensive reviews have isolated the major predictors of breast cancer screening among African American women (17,18,19,20,21), the findings have not been incorporated within a unifying theoretical framework.

In response to the lack of published reviews relating to participation in risk assessment programs among African American women, and the lack of unifying theoretical approach taken in published reviews concerning predictors of breast cancer screening among African American women, in this paper we provide an integrated, theory-guided comprehensive review of this risk-related literature. We outline the Cognitive-Social Health Information Processing (C-SHIP)

model for understanding genetic risk assessment participation and breast screening behaviors among African American women. We review the cognitive-affective factors that account for variability in women's responses to cancer risk, both in terms of adherence to cancer screening and in interest in genetic risk assessment participation. We then provide two integrative perspectives on this literature by focusing on signature attentional styles of processing health-related information (i.e., high versus low monitoring) and the social network model. Finally, we discuss implications of these findings and future directions to address breast screening adherence and genetic risk assessment participation among African American women.

A COGNITIVE-SOCIAL THEORY FOR BREAST CANCER SURVEILLANCE BEHAVIOR

The Cognitive-Social Health Information-Processing model (C-SHIP; 22) is a broad theoretical framework that informs the design and assessment of behavior change treatments in the context of cancer prevention and control (23). This model is derived from the summing of findings and theorizing from diverse relevant sub-areas of cognitive-behavioral science (e.g., 24, 25) and from clinical psychological interventions (e.g., 26), rather than simply reflecting the contributions of a single theory (e.g., 27). The model postulates that individuals can be characterized by their cognitive and affective responses to health-relevant threats, and it is these responses that determine their dispositional tendencies or "behavioral signatures" towards health-enhancing vs. health-diminishing behaviors (28, 29). The C-SHIP model has been widely used to conceptualize behavior change and has been empirically validated in diverse health contexts, including cancer risk (22, 29, 30, 31, 32).

According to the model, there are four distinctive cognitive-emotional processes that underlie the information processing of cancer risk information: 1) individuals' self-construals of

their risk, including their knowledge levels and perceived risk; 2) their expectancies about the benefits and limitations of specific cancer-related actions; 3) their health values (e.g., fatalistic attitudes about cancer); and, 4) cancer-specific emotional distress. By delineating the specific cognitive and affective variables that influence individual differences in the practice of health-protective behaviors, the C-SHIP model provides a blueprint for the design of tailored interventions to facilitate those behaviors and improve health outcomes. As applied to African American women, the C-SHIP model identifies the cognitive-affective factors that need to be addressed when facilitating informed uptake of risk assessment and better adherence to surveillance protocols. Each of the four C-SHIP cognitive-emotional processes will now be systematically reviewed with respect to breast screening adherence and genetic risk assessment uptake among African American women.

Breast Cancer Related Self-Construals: Knowledge and Perceived Risk

Women who lack sufficient knowledge of available surveillance regimens cannot take advantage of them (e.g., 33). Mammography adherence is generally related to knowledge about breast cancer risk and recommendations, such that higher levels of knowledge predict greater utilization (34, 35, 36, 37). Among African American women, levels of breast cancer related knowledge are generally low. Therefore, it is not surprising that adherence to screening recommendations is less than optimal for these women (5,38).

Perceived risk for breast cancer is another factor that influences participation in risk assessment and screening programs among African American women. Studies examining perceived risk for breast cancer among African American women at average risk for breast cancer have yielded inconsistent results. Although there is some evidence for underestimation of risk (39, 40), on balance, there is more evidence to suggest that African American women

overestimate their risk for breast cancer relative to Caucasian and Hispanic women (12; 41, 42). Further, among at-risk African American women with a family history of breast cancer, perceived breast cancer risk is greater than for average risk African American women (43), but lower than for at-risk Caucasian women (44, 73). Increased perceptions of risk have been linked with increased worries about the affected relative, and younger age among women at increased risk for breast cancer (44,41,45). Inaccurate risk estimates among African American women may be attributed to lower levels of cancer breast cancer-related knowledge (46), and risk-related intrusive thoughts interfering with the processing of risk information, (47).

The accuracy of risk perceptions among average risk African American woman is not related to breast cancer screening adherence (77). However, among at-risk women, accurate knowledge of breast cancer risk is associated with screening practices, albeit at less than recommended frequencies (8). Further, African Americans who overestimate their risk may even engage in excessive breast self examination (44); a less effective screening approach than mammography.

Lower perceived risk is related to decreased interest in genetic testing among African American women (48,12,43). Accuracy of risk assessment may be improved through educational intervention (47, 49), and, when risk information is provided within the context of a trusting relationship, interest in genetic testing may increase (50). However, actual uptake of genetic testing does not appear to necessarily follow expressions of interest (50).

Breast Cancer Related Expectancies and Beliefs

Perceived benefits (i.e., pros) and limitations (i.e., cons) about breast cancer risk have been associated with health-protective behaviors (51). In the screening context, a number of studies conducted among predominantly Caucasian women have documented a relationship

between women's perceived benefits of mammography and their utilization adherence (e.g., 35, 52, 34, 53, 36, 37, 54). Conversely, perceived barriers (e.g., expectations of pain) have been consistently associated with reduced mammography adherence (e.g., 35, 52, 37, 55). Similarly, in studies specifically focusing on African American women, beliefs that early detection can lead to cure of breast cancer, and belief in taking charge of one's own health (56) are associated with increased mammography utilization (57, 38), while perceived barriers related to mammography (e.g., fear of radiation, perceptions of lack of healthcare access) are associated with decreased mammography use (58, 59, 60, 61). Utilization of clinical breast examination within African American subgroups (US-born African Americans and English-speaking Afro-Caribbeans) is associated with belief in the efficacy of clinical exams, whereas infrequent use is associated with lack of trust in the efficacy of cancer treatments (Carol Magai, personal communication).

The little research conducted with African American women in the genetic risk assessment context suggests that readiness to participate in genetic risk assessment can be largely attributed to perceptions that the advantages of testing outweigh the disadvantages (62). Indeed, a recent study shows that African American women are interested in genetic risk assessment to the extent that they believe that testing outcomes would be of benefit to themselves and to their families (63). Further, despite having lower levels of knowledge, African American women report more positive attitudes about the benefits of genetic risk assessment (48,64). On the other hand, African American women perceive the cost and availability of BRCA1/2 testing as salient barriers to participation (48, 63).

Breast Cancer Related Values and Goals

Fatalistic beliefs (i.e., believing, for instance, that there is no use in getting tested or screened, since cancer is inevitable) are prevalent among African American women, particularly

those who are lower income, less well-educated, and unemployed (65, 66). Individuals who are characterized by higher levels of fatalistic beliefs report significantly lower levels of adherence to screening for breast cancer, particularly among low-income (67) and Afro-Caribbean women (68, 69, Carol Magai, personal communication). Fatalistic attitudes, like other shared national values and belief systems (70, 71, 65), act by lowering self-efficacy and expectancies about the outcomes of health-related behaviors, in turn reducing the motivation for an individual to persist in enacting specific health-protective behaviors such as mammography (22). Within the genetic risk assessment context, fatalistic thinking among African Americans concerning the inevitability of cancer diagnosis is related to low levels of interest and low likelihood of participation in such programs (63). In a related vein, women with high levels of spiritual faith, that is women who believe that a higher power determines who gets cancer, (who are, therefore, presumably less reliant on the medical system) report less likelihood of participating in genetic risk assessment (72).

Breast Cancer Related Emotional Distress

Among women at increased risk for breast cancer with at least one first degree relative (FDR) diagnosed with breast cancer, African American women report significantly greater concerns and worries about their affected relative, and heightened avoidance of breast-cancer related thoughts and feelings compared with Caucasian women (73). With respect to screening behaviors, some research points to a positive relationship between breast cancer related distress and adherence (e.g., 74, 75), whereas other research points to a negative relationship (e.g., 76, 77). In studies linking higher distress with greater screening adherence, cancer worry was at a moderate level, whereas cancer worry reported in Caryn Lerman and colleagues' (76, 77) studies was at a level that interfered with daily functioning. Therefore, an inverted U-shaped relationship

between distress and screening behavior appears to exist, whereby moderate levels of cancer worry motivate screening behavior, but extremely high or low levels of psychological distress inhibit cancer screening (22, 23). Within the African American community, fear of cancer is reported as one of the most important reasons for not participating in mammography screening programs (78, 79). However, among FDRs of African American women with breast cancer, fear of cancer is also associated with excessive use of breast self-examination (80).

Interest in genetic risk assessment is associated with increased levels of cancer-related emotional distress (81, 82), but decreased understanding and comprehension of genetic risk feedback (e.g., 12). Moreover, fears about how to emotionally deal with genetic risk feedback are central reasons reported by African Americans for not wanting to participate in genetic risk assessment (63).

ATTENTIONAL STYLE

According to the C-SHIP model, individuals are characterized by distinctive styles or behavioral signatures in how they select, encode, and manage health information, and how they react to it (28). In particular, these behavioral signature attentional response styles have been systematically explored in terms of high monitors (who scan for, and magnify, threatening cues) and low monitors (who distract from, and downgrade, threatening information; 28). There is evidence to support the universality of these behavioral signatures, with consistent effects emerging across diverse ethnic (e.g., Caucasians vs. African Americans) and cultural groups (e.g., European versus American) (28, 83). The two attentional styles are characterized by different organizations in the structure of their self-construals, beliefs, and behaviors (83).

Under routine stress conditions, high monitors (who are more attentive to health threats) are more likely to behave in an adaptive fashion, demonstrating increased adherence to

recommended screening regimens (84). However, under conditions of high threat (e.g., feedback of an abnormal screening result) high monitors respond with heightened levels of risk-related anxiety and avoidance (32, 72). This response can ultimately undermine and interfere with their ability to maintain required health-protective behaviors (22, 85). In contrast, low monitors -- who are less focused on health threats -- are likely to ignore cancer threats from the outset and thereby demonstrate poor screening adherence overall (22).

Attentional style also appears to be an important determinant of interest in genetic risk assessment and testing. High monitors are more likely to report increased perceived risk for breast cancer, more pessimistic attitudes about their vulnerability to breast cancer, and increased breast cancer-related distress, compared with low monitors (28, 72, 31, 86). Hence, they are more likely to express greater interest in participating in genetic risk assessment and testing, even if their doctor recommended against it (87). However, high monitors are also more likely to have expectations of increased adverse psychological consequences following testing, which may influence the genetic risk assessment decision-making processes (81). Similarly, patterns of communication of genetic risk assessment results to family members are influenced by attentional style. Among women with a putative hereditary breast cancer pattern undergoing breast/ovarian genetic risk assessment, high monitors report greater intentions to communicate positive test results to family members and to engage in strategic planning for this communication (88). Taken together, these results suggest that interventions designed to promote breast screening and appropriate uptake of genetic risk assessment programs need to take account of the unique cognitive-affective profile of the individual (30, 89), as well as the unique characteristics of the African American culture.

SOCIAL SUPPORT

Considerable evidence supports the importance of the social support system (i.e., family, friends, physicians) in increasing breast screening adherence among African American women; referred to here as the Social Network perspective (see 90, 91, 92). African American women are embedded within a context of nested systems, families, peer groups, organizations (e.g., medical centers, worksites) and larger communities (93). Within this context, the woman creates a network of unique relationships with which she exchanges emotional (e.g., esteem, trust), appraisal (e.g., affirmation, social comparison), informational (e.g., advice, directives) and instrumental support (e.g., money, time) (94, 95). These support sources form the most salient norms and values to which the woman responds, as well as critical information convoys, subsequently influencing her breast cancer surveillance behaviors. As a source of accurate information, the physician may also influence screening and risk assessment decisions and behaviors (96,97,98,99). Physicians, however, are less likely to encourage breast cancer screening (100, 101) or to discuss genetic testing (48) with African Americans than with other women.

African American women are also particularly likely to experience the barrier of having social networks who are fearful of orthodox medical care, and thus not able to encourage the women to engage in breast cancer surveillance behaviors (102). For example, the screening practices of relatives and friends has been found to influence surveillance among African American women (103,104). Further, participation in breast screening has been linked with increased number of social ties (105), and being married or living with a partner (106). Although the data are limited, the participation of African American FDR's in risk assessment programs seems related to their concerns for, and care of their affected relative (73).

IMPLICATIONS AND ONGOING EMPIRICAL DIRECTIONS

It is increasingly recognized that psychosocial interventions can be effective in promoting appropriate interest in, and use of, cancer risk assessment programs, as well as promoting screening adherence (89, 107). However, the specific content and structure of these interventions are just beginning to be linked to state-of-the-art theory and research (108,16). Risk counseling protocols have been shown to reduce breast cancer specific distress, knowledge of risk, and risk perception, particularly for FDRs with less education, thereby improving program attendance as well as increasing adherence to screening recommendations (108, 109, 110). However, some data suggest that generic interventions, developed for Caucasian women, are not effective with underserved populations (e.g., 12, 16). Thus, new intervention approaches are needed that are evidence-based and built on an empirically-derived understanding of the unique barriers and facilitators of breast cancer health behaviors among African American women. Further, these interventions need to be guided by well-formulated theoretical frameworks from the health behavior context.

Over the past decade, we have used the C-SHIP model to conceptualize behavior change in diverse health contexts, including cancer (22, 23). Guided by this model, we have developed the Cognitive Affective Processing (CAP) intervention to facilitate health- protective behaviors, such as adherence to diagnostic follow-up for breast, cervical, and prostate cancer screening, and decision making about breast, ovarian, and prostate cancer risk assessment (e.g., 111). This intervention is tailored to the distinctive cognitive and emotional processes that underlie the information processing of health risk information, including the individual's knowledge and self-construals of risk; her expectancies about the benefits and drawbacks of specific health responses; her health values (e.g., fatalistic attitudes about health); her cancer-specific emotional

distress; and her self-regulatory strategies for managing risk-related distress and generating action plans for adherence to health-protective behaviors. The CAP involves realistic anticipation of the individual's potential cognitive and emotional reactions to health risk feedback, as a function of her unique cognitive-affective profile, through structured role play and pre-living of the experience. CAP has proved feasible to undertake with low-income, inner-city minority women for smoking cessation in an ongoing study.

Funded by the Komen Foundation, we are extending this work by developing and testing a cognitive-affective-social network (CASN) intervention, designed to facilitate interest in breast cancer risk assessment, as well as adherence to breast cancer-screening recommendations. As in CAP, the CASN intervention applies established cognitive-behavioral methods to enable individuals to assess and address their responses to risk feedback (e.g., 30, 112). However, the CASN also incorporates an additional social network approach. Social network perspectives suggest that an intervention that concomitantly targets the members of the woman's social network, as well as the woman herself, should be maximally effective in encouraging behavior change in the at-risk woman, particularly among African Americans.

To accomplish these goals, we are conducting a two-arm randomized trial (N=120) to examine the feasibility and preliminary impact of the CASN intervention compared with a General Health Information (GHI) control (to equate for time and attention). For both conditions, participants attend one group counseling session that involves a triad of individuals: the FDR, her spouse/partner, and a salient member of her social group. The CASN intervention targets both breast cancer screening adherence and risk assessment uptake, through a two-part collaborative strategy between the participant, her family member/friend and the clinician: 1) selecting a problem to work on or "go-around", and 2) a problem solving process. The aim is to

modify the social network's approach to risk assessment and screening so that the FDR is supported and encouraged to maintain recommended screening regimens and to seek out risk assessment counseling where appropriate.

During the CASN session, the specific cognitive (e.g., perceptions of risk, pros and cons of risk assessment/breast screening, fatalistic attitudes) and affective (e.g., psychological distress) barriers to engaging in breast cancer screening and making decisions about participation in risk assessment programs are assessed and addressed. Information about breast cancer risk factors, screening, and risk assessment programs is first provided to address knowledge, including information about the availability of risk assessment programs in the women's local area. Next, the health educator, the participant and her spouse/partner and friend explore the individual's thoughts and feelings with regard to risk assessment/breast cancer screening, including the participants' understanding and accuracy of her risk, attitudes about the pros and cons of risk assessment/breast screening, fatalistic attitudes, and breast cancer related distress.

Through the use of the thought sampling procedure, the individual is encouraged to report her thoughts about a particular issue or event, such as not being able to fully understand the concept of genetic risk, but being afraid of dying from breast cancer, through questions and probes. Use of this approach elicits "interfering self-statements" which become targets of corrective information and feedback (113). Concomitantly, we systematically train the FDR and the accompanying members of her social support network in appropriate breast cancer surveillance approaches and risk assessment options for at-risk women, thereby altering the type, quality, density and amount of support provided to the FDR for adherence. To equate for time and attention, GHI participants and their social network members will receive general

information concerning guidelines for a low-fat/high fiber diet and a regular exercise program and, for those who smoke, smoking cessation advice and assistance.

Following the group counseling session, all FDRs receive three booster telephone calls. Telephone calls to CASN participants will reinforce the cognitive and affective messages (e.g., reducing fatalism) and the problem-solving approaches (e.g., building/establishing social networks oriented to adherence) presented in the counseling session. For GHI participants, the telephone calls will focus on general health education messages.

Taken together, this study will allow us to compare the feasibility and impact of an enhanced counseling intervention, tailored to the specific cognitive and affective barriers to screening adherence and risk assessment participation, drawing on the individual's social network as a resource to provide instrumental and emotional support. This pilot study will provide the basis for a larger scale clinical trial and in so doing, should make a significant impact upon the rate of breast cancer mortality in this population. The results have implications not only for the design of breast cancer risk assessment and screening interventions, but also for the design of interventions to promote the effective use of chemoprevention and other emerging regimens among underserved high risk women.

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